Monitoring Educational Participation in Children with Severe to Profound Intellectual Disability in Rural Districts of the Western Cape

A descriptive analytical study

by

Karlien Spangenberg

Thesis submitted in fulfilment of the requirements for the degree of

MASTER OF SCIENCE IN PHYSIOTHERAPY

Division of Physiotherapy

Faculty of Health Sciences

Department of Health and Rehabilitation Sciences

UNIVERSITY OF CAPE TOWN

June 2018

Supervisors:

Professor Jennifer Jelsma

Associate Professor Judith McKenzie

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Abstract

Subsequent to a High Court ruling, educational support was made available to children with severe to profound intellectual disability in the Western Cape in the form of multi-professional outreach teams. Neither the attainment of learning outcomes nor indicators of educational performance have been reported for those receiving these services. The use of the P scales, which were developed in the United Kingdom to specify educational attainment targets, have been piloted by the outreach teams. However, the reliability and responsiveness to change of these scales needed to be established within the Western Cape context.

This research aimed, firstly, to develop a profile of the children in receipt of support from the rural outreach team through the use of a record review, which could inform future service delivery. The second aim was to validate the P scales in the context of rural districts in the Western Cape. The third was to document the nature, content and frequency of intervention by the team. The fourth aim was to identify variables that might be associated with the attainment of learning outcomes.

The study population of 498 children had a mean age of 9.9 years and 60% were male. Afrikaans was the home language for most (68%), followed by IsiXhosa (28%). Only 29% lived with both parents, 33% with a single parent, and a high number were in foster care (13%). The most prevalent associated health condition was found to be cerebral palsy (27.9%). Many presented with more than one condition, frequently involving epilepsy. Prominent aetiological factors were classified as maternal and child (25%) or congenital and hereditary (23%) conditions. Chronic medication was used by 37%, but information on other medical procedures was largely unavailable. Children (62%) received additional therapeutic services from the Western Cape Department of Health (62%) and other therapists, including students. The need in terms of wheelchairs and buggies was met, but access to standing frames was limited. Transport was largely available through the special care centres. Where the classification systems were applied, most children were found to be mobile, with good hand function. However, most children were “seldom effective” in communicating their needs. For all subject areas measured by the P scales, peaks were observed at P1(ii) and between P4, P5.

Reliability, internal consistency and responsiveness of the P scales were established through a longitudinal study design, using two routinely assessed scores of 83 participants - done at least one year apart. The internal consistency (reliability) (Cronbach’s alpha) was very high in the whole sample (.99) but somewhat lower in the children with a higher performance level (.71). The scale was responsive and the Sign test indicated improvement in every item across time, with at least 39 of the 83 children improving from the first to the second assessment. Known group validity was determined by comparing P scale scores to scores across the different levels of the three routinely applied classification scales [gross motor (n=181), manual ability (n=181) and communication (n=177)]. In every case, the scale item score was significantly associated with the level of the corresponding classification system. Concurrent validity, using the Vineland Adaptive Behaviour Scales II as the gold standard with 41 participants, was demonstrated. Each item was significantly correlated with the relevant specifying performance attainment targets of the Vineland Adaptive Behaviour Scale item (range rho=.61-.84). Feasibility and acceptability of the P scales were determined by twelve professionals in the field. Eight reported them to be useful. It was concluded that selective, routine use can be valuable in tracking learners’ performance.

A descriptive analytical longitudinal record review of 83 participants was used to establish which factors were related to educational performance over a period of at least one year. Age, language concordance, medical conditions, independent mobility, effective communication, comprehensive support and individual intervention from Western Cape Education Department team members did not emerge as significant indicators of change in participation ability of this study population.

Recommendations include the following. The high number of children in need of medical support implies that there should be good working relationships between teams, centres and community-based services from Department of Health. It is imperative that rehabilitation services remain in place, with optimal use of additional services and interdepartmental communication on the operational level to ensure that every child receives the necessary therapeutic support. The P scale scores indicated that there were two groups of children, those with very limited performance (P1) and those with improved ability to participate (P4, P5). As their support needs are likely to be different, this should be factored into the programmes and training of support staff. It is strongly recommended that all children receiving support from WCED should have their information entered using the same data base and this information should be amalgamated centrally to inform future planning of services and training within the region.

The P scales indicated that, when used within the context of the rural team, these scales were both valid and reliable. It is therefore recommended that a similar approach to administration, namely collaborative scoring after training on assessment procedure, be adopted throughout the province. It was also encouraging that the P scales were responsive to change and approximately half of the children showed improvement over a period of six months or more. The high correlation between the scales in children with the most profound impairments implies that it might be sufficient to administer only one or two of the four scales in this group.

The P scales have the potential to be rolled out alongside the newly developed Learning Programme for Learners with Severe to Profound Intellectual Disability. With the emphasis on educational performance, it could become the standard assessment tool. The instrument would then need to be validated within a larger context, with training of administrators and standardisation of the assessment process a prerequisite.

Acknowledgements

To God be the glory, for without Him I would not have been in this privileged position of supporting children with severe to profound intellectual disabilities. Neither would I have had the strength and endurance with which to see this thesis through to the end.

Sincere thanks to my family (including my extended family), who have supported and encouraged me on this journey. Each and everybody made sacrifices and took over some of my tasks in order to accommodate my hours in front of the computer.

Thank you to my supervisor, Emeritus Professor Jennifer Jelsma. Her belief in me and constant attempt “to get me hooked”, made me grab the opportunity – though being very weary of the journey. She understood my critique-sensitive nature well and I admired her for the overwhelmingly positive attitude when reviewing my work.

Also to my co-supervisor, Associate Professor Judith McKenzie, from whom I have learned tremendously - about the context of severe to profound intellectual disability, the importance of parental involvement and the importance of a responsive environment.

A huge thanks to my rural colleagues, Winnie Janse van Rensburg, Elizma Killian and Jenni Geldenhuys. They have shared my vision in many respects and, as a result, did much more than the basic requirements of our provincial service delivery model. They have encouraged me, scrutinised my thought processes and, above all, contributed significantly in documenting their intervention and the execution of assessments.

Last, but not least, to my provincial co-ordinator, Heidi Myburgh and other provincial team members, I am most grateful for their kind words of encouragement.

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Glossary and Acronyms

Academic attainment

Academic attainment for children with SPID is seen as reaching the next level of performance in the major life area and the environment of education (ICF-CY) [1]. In this study educational attainment is measured by using an ordinal scale named P scales [2]

Care centres

According to the Children's Act, No. 38 of 2005 [3] this term includes the following facilities:

- Child and youth care centres
- Drop in centre
- Partial care facilities
- Special care centre
- Stimulation centre
- 24 hour facilities

The facilities in this study are mainly special care centres. These are community-based day care facilities that offer some kind of daily programme. They are intended to provide not only care but also education and stimulation for children with various disabilities (mainly severe to profound intellectual disability).

Care worker

Staff employed at special care centres to provide physical care for children, including feeding, toileting and washing. Care giving staff have an important educational role to play by offering care in a way that promotes independence for children with severe to profound intellectual disability.

Developmental delay

The term used for severely slow attainment of developmental milestones in two or more domains of typical development.

Gross motor capacity, capability and performance

- Gross motor **capacity** is the ability to move, maintain and change positions in space as measured in a standardized environment [4, 5]. These abilities fall under the activity domain according to the ICF [4, 6]. Motor capacity should be well established by age five [4]. In typical development, as children age, other intrinsic and extrinsic factors become the determinants of daily-life mobility instead of motor capacity [7]. Even in less severe forms of cerebral palsy, gross motor capacity is not fully established, even in older children with good functional skills [8].
- **Gross motor capability** is a term to reflect the skill developed through practice in a particular physical environment (not

generalized) and thus what a person can potentially do in daily life [4, 5].

- **Gross motor performance** indicates how the child actually applies skills in different environments, when other personal and social factors also contribute to the execution of the skill under observation [4, 5].

Inclusive education

This is defined on page 16 in Education White Paper 6 (2001) [9] as a system which acknowledges that "all children can learn and that all children need support" and it accepts that "all learners are different in some way and have different learning needs which are equally valued and an ordinary part of our human experience". It is "about enabling education structures, systems and learning methodologies to meet the needs of all learners" which "respect differences in learners, whether due to age, gender, ethnicity, language, class, disability or HIV status." It is "broader than formal schooling and acknowledges that learning also occurs in the home and community, and within formal and informal modes and structures". Inclusive education is about "changing attitudes, behaviour, teaching methodologies, curricula and the environment to meet the needs of all learners." The essence lies in "maximizing the participation of all learners in the culture and the curricula of educational institutions" and "empowering learners by developing their individual strengths and enabling them to participate critically in the process of learning."

Learning (as it pertains to the child with severe to profound intellectual disability)

Learning takes place "through an *integration of sensory perceptions and physical movement. Through frequent repetitions of actions that bring about certain effects, sensory-motor action schemes are developed that are the foundations for single problem solving behaviour"* **(Piaget)** [10].

Learned behaviour can be then be applied to develop skills (see below). In children with severe to profound intellectual disability, the focus is on the development of everyday skills of self-care, domestic tasks, use of money, language and communication [11].

Educational outreach services

Educational support provided to out-of-school children, who might not otherwise have access to such services. Usually the outreach teams are itinerant - meeting those in need of outreach services at the locations where they are.

Participation

According to World Health Organization – International Classification of Functioning, Disability and Health – Child and Youth version, participation represents "*involvement in a life situation"* and ***participation restrictions*** *are "problems an individual may experience in involvement in life situations".* Two qualifiers for this component are performance (what a child does do in a daily environment) and capacity (what a child can do in a standardized environment) [1].

Severe to profound intellectual disability (SPID)	Impairment of general mental ability, which leads to deficits in adaptive functioning, ranging from severe to extreme (see Chapter 2 for detailed definition according to DSM-5)
Skill	A skill is a learned ability to carry out a task with pre-determined results within a given amount of time or energy. It is the ability and capacity acquired through deliberate, systematic and sustained effort to carry out and adapt complex activities, smoothly.
Western Cape Forum for Intellectual Disability	A Western Cape based forum for non-governmental organisations, which work with persons with ID.

Acronym	**Term**
AAC	Alternative and augmentative communication
ADL	Activities of daily living
CAPS	Curriculum Assessment Policy Statement
CDG	Care dependency grant
CFCS	Communication Function Classification Scale
CSTL	Care and Support for Teaching and Learning
DSM-5	Diagnostic and Statistical Manual of Mental Disorders 5th Edition
FASD	Foetal alcohol spectrum disorder
GMFCS	Gross Motor Function Classification Scale
ICF	International Classification of Functioning, Disability and Health
ID	Intellectual disability
IDD	Intellectual developmental disorder
IE	Inclusive education
IQ	Intelligence quotient
ISP	Individual support plan
LOLT	Language of learning and teaching
MACS	Manual Ability Classification Scale

NCS	National Curriculum Statement (Gr R-12)
NGO	Non-governmental organisation
NPO	Non profitable organisation
PID	Profound intellectual disability
PWID	People with intellectual disability
SCC	Special care centre
SIAS	Screening, Identification, Assessment and Support
SPID	Severe to profound intellectual disability
UK	United Kingdom
VABS II	Vineland Adaptive Behaviour Scale II
WCED	Western Cape Education Department

Chapter 1. Introduction

1.1 Background to the study

The UN Convention on the Rights of the Child (UNCRC) in 1989 [12] led to a world conference on "Education for All" in 1990 which affirmed education as a fundamental human right [13]. In conjunction with the UN Convention on the Rights of Persons with Disabilities (UNCRPD) [14], policies to address marginalization and exclusion of people with disabilities were subsequently instituted. As a result there has been a growing recognition globally that the child with intellectual disability (ID) may not be regarded "ineducable", as they were labelled in the past [11]. Education authorities in high income countries were the first to recognise that, irrespective of the severity of the disability, a child should not be excluded from educational opportunities and they took incremental steps in accepting responsibility for educating this vulnerable group of children [11].

Despite these global initiatives, educational reforms in low-to-middle income countries have been slow [15]. Poverty [16, 17], limited resources [18, 19], a lack of uniform definitions and datasets [15, 20] and a scarcity of research in Africa proves to be some of the challenges [21]. The available literature reveals that there are a lack of educational policies [22] and access to education in most of Africa [21].

South Africa, however, has a constitution which recognises the rights of the person with a disability, including ID [23]. The constitutional acknowledgement of the needs of the child with a disability is expressed in Education White Paper 6, a policy on special needs education [9]. Resulting from this international paradigm shift and based on the South African Constitution, the right to education of children with ID is now recognised. Yet the social exclusion of persons with severe to profound intellectual disability (SPID) is still exacerbated by stigmatization and discrimination [22, 24].

Intellectual disability involves impairments of general mental abilities that determines how well an individual copes with everyday tasks. Individuals with severe to profound intellectual disability (SPID) demonstrate extreme functioning deficits with the implications that they require lifelong support across all life environments [19, 25]. Participation in activities of daily living (ADL) for the person with SPID can therefore only take place through direct support persons [26].

This study seeks to understand the nature of educational attainment of children with SPID in light of the implementation of educational support in the Western Cape.

Despite the formulation of various policy documents on inclusive education in South Africa, children are still being excluded from educational services because of their disability [27, 28]. The Department of Basic Education (DBE) in South Africa initially adopted a policy of gradual transformation towards inclusion of children with disabilities [29]. The government's contention was that these children were "unlikely to benefit from any kind of education" and that resources were too scarce to provide for the needs of children with SPID [30] .

The Western Cape Forum for Intellectual Disability (WCFID) was not satisfied with this approach and successfully argued in the High Court in 2010 that both the national government and the Western Cape government were not fulfilling their obligation towards every child's constitutional right to "education, equality, human dignity and protection from neglect and degradation" [23, 31].

The national government responded to the High Court ruling by drafting another policy to align with the Education White Paper 6 [9] and, amongst others, to align with a crucial policy on Screening, Identification, Assessment and Support (SIAS) [32]. The inaccessibility of the South African national curriculum (NCF) and Curriculum Assessment Policy Statements (CAPS) for children with SPID led to the simultaneous development of policy documents: *Policy for the provision of quality education and support for children with Severe to Profound Intellectual Disability* and *A Learning Programme for learners with Severe to Profound Intellectual Disability*. Both of these have been through public comment and are in the process of being finalised [33, 34]. In 2017 a conditional grant was allocated, which enabled the temporary appointment of itinerant teams on a national level [34]. These steps were taken by the national government, in accordance with the National Development Plan - which recognised that inclusion is the key to enable everyone to participate effectively in society [35] .

The court ruling in favour of the WCFID necessitated the Western Cape Education Department (WCED), in collaboration with other provincial departments, to conduct an audit of the community based special care centres (SCCs). Four inter-professional teams were subsequently appointed to render educational and therapeutic support to children with SPID [36]. These teams became operational in SCCs in the WC in 2012. Guided by the content of the court ruling the teams established, through trial and error, a novel method of service delivery [36]. Existing assessment material and programs were considered, and elements thereof incorporated into a draft framework[1]; yet there existed no evidence as to their efficacy and contextual appropriateness in the extremely poorly resourced settings in which educational services were much needed.

Based on the audit conducted by WCED, it was advised that programs needed to be supported and monitored continuously, because care workers were only experienced in caregiving and not education. Members of the outreach team, in conjunction with the Department of Health and Rehabilitation Sciences at the University of Cape Town (UCT), concluded that different options for provision of educational support to children with SPID could be explored only through the development of individual support plans. Programs should then be developed to address the needs identified. McKenzie et al. advocated for minimum standards and professional qualifications to be developed [36].

1.2 Rationale

Resources are limited in low- and middle-income countries and ID has an impact on the whole of society, hence the need to measure the burden thereof [18, 19, 37]. South Africa is a middle-income country with limited access for children with SPID to health and education services, an absence of custom designed programs for ID, lack of support for their families and very little data collection to

[1] Draft Framework for Therapeutic and Stimulation Programme: Children with severe to profound intellectual disability, developed by Provincial CSPID team November 2012, submitted to WCED

quantify the situation [21]. To fulfil the requirements set out in court [31], a reflection of the cost and process of service delivery should rightfully be done by rigorous application of systematic monitoring [38], starting with the impact on the individual [39]. In order to measure the efficacy of the direct services of professionals, these results should be analysed and the implications thereof strategically embedded into operational planning [39]. This enables the development of effective interventions [40] and quality management, and ensures congruency between educational policy and practice [39].

If learning has taken place, the child with SPID may have more control over his environment, with a resultant improved quality of life [41, 42] for both child and family. The outcome measure, with which to determine whether learning has taken place, should ultimately also be suitable to empower the parents. It is therefore essential that educational services can monitor and quantify the impact of improved quality of life on an individual level, so that the family and society may acknowledge that these children's right to education is being realised.

Finding responsive outcome measures should, therefore, be regarded as a cornerstone for the design of protocols and strategies to enable evidence informed implementation of support. With a better understanding of the population and its context, future research would then be able to produce comprehensive analytical accounts – available for critical review by policy makers and service managers. The ultimate aim is that an agreement should exist as to which assessments and procedures are used across the globe [20]. It is also important to document intervention in a systematic manner in order to gain knowledge about practices leading to positive results [43]. If standardised assessment protocols and frameworks are used in local educational interventions, results may be comparable and would be of international value [36].

This was the rationale behind the development and validation of an educational database for children with SPID in the WC. The findings of the outreach team were published in September 2016 (included as Appendix I) and predicted that relevant changes - which would indicate that learning and skills development took place - could be detected [44] through the use of:

- Classification systems to describe the severity of impairment and to guide adaptations to activities [45-47]
- Vineland Adaptive Behaviour Scales II to determine adaptive functioning [48, 49]
- P scales to assess and facilitate participation in structured activities [50]

Of these, the P Scales was the only measure specifically developed to monitor performance and change in children with a large spectrum of intellectual ability. The P scales were developed in the UK in response to the movement towards Inclusive Education. They are utilised alongside the National Curriculum in a fully inclusive education system - "adapted and differentiated to meet the needs of all children, including those with profound and multiple learning difficulties" [11]. These scales function similarly to the scores of national tests, which make it possible to measure progress - not previously possible on the National Curriculum scale [11, 51]. Various government driven studies were conducted in the process of developing (1998) and revising (2001 and 2004) these guidelines. In a comprehensive study on a large sample of the population with special education needs, Ndaji & Tymms (2010) found the P scales to be valid and efficient in differentiating the curriculum in order to accommodate the child with SPID and other barriers to learning [51].

The joint WCED and UCT research task team also argued that without inclusion of the profile and performance of children with SPID into the Education Management Information Systems (EMIS), this group of children would stay excluded [44]. A national evaluation of attainment through tracking, assessment, intervention and parent interviews is needed. These elements are included in the SIAS process [32]. However, no clear directive exists for this group of learners in terms of assessing learning outcomes.

The key to contextually appropriate, evidence informed practice lies in the answers to these research questions: What is the typical profile of children with SPID in rural parts of the WC who receive education from the rural WCED rural team? Does the P scales, as the proposed measure of educational attainment, demonstrate contextual validity? Do the children show improvement in performance over time and are the P scales adequately responsive to detect this change? Can factors be identified which are predictive or associated with change in educational performance?

1.3 Aims and objectives

The aims of the study were two-fold. One was to document the personal and treatment characteristics of the children with SPID in rural parts of the WC to determine whether any factors were associated with change in educational performance. The second aim was to assess the validity and responsiveness of the P scales (included in the educational database for children with SPID), as a tool for monitoring educational performance.

The specific objectives were, using the information included in the database related to children with SPID, in rural educational districts of the Western Cape:

- To describe the characteristics and needs of these children
- To establish whether the P-Scales is a psychometrically sound outcome measure within this context
- To document the nature, content and frequency of intervention by the team
- To pilot the use of the P scales as a participation-level measure of educational performance in identifying which factors were associated with an increased chance of improved performance

1.4 Research setting

Children with SPID, living in communities where resources are scarce, face considerable barriers in accessing the education system. According to the South African Census 2011, these include infrastructure, transport, special schools with extensive waiting lists and inadequate levels of support to access the curriculum [52]. Special care centres (SCCs) were established to address these problems with most initially run informally by mothers of disabled children [53].

Most SCCs are community-based day care facilities that offer some kind of daily programme, intended to provide not only care but also education and stimulation for children with SPID. Some of these centres are run by non profit organisations (the NPO sector), registered with the Department of Social Development (DSD) and receive support from various state departments. Licencing of these centres is done by the Department of Health (DoH) and jointly the state departments monitor and evaluate the compliance of funded NPOs [19, 54]. Not all SCCs in the WC were, however, registered and licenced at the time of the study and many ran on minimal resources. SCCs consequently range from being fully staffed and equipped centres to volunteers caring for children in single rooms in houses or informal dwellings.

Resulting from the WCED audit and in collaboration with other provincial departments, four inter-professional teams were appointed on contract basis in 2012 to work in SCCs in eight educational districts of the WC. Each team consists of a psychologist, a learning support educator, an occupational therapist, a physiotherapist and a speech and language therapist. Three teams were allocated to four Metropolitan districts and one team (hereafter referred to as 'the rural team') to the rural areas of the WC to deliver educational and therapeutic support services . The support services delivered by the rural team are described in more depth in order to give insight into the context of educational support.

Individual support plans form the basis of educational support to children with SPID, yet by 2012 the specific outcome measures used were not reported on [36]. Although the research task team identified possible standardized outcome measures [44], these were not in routine use by all four of the teams. The rural team piloted the use of the classification systems, the P scales and the Wee-FIM. The P scales and classification systems were chosen so that observations from all team members - therapists, educators and psychologists - could be taken into consideration [44]. These observations mainly take place within the daily functioning of the classroom, but information from interviews with parents and direct support workers, and the results of profession-specific, standardized assessments are all considered in the allocation of scores and planning of both individual and group support.

Provincial figures show that by March 2017, the four outreach teams supported 1785 children with SPID in 54 SCCs spread across seven educational districts of the WC[2]. During the time of the study, between September 2014 and March 2017, 501 of these children (in 20 of these SCCs) were in receipt of educational and therapeutic support services in the three rural educational districts of the West Coast, the Cape Winelands and the Overberg. Each district has its own unique context, which affected this study population in one way or another.

The Cape Winelands has the largest population of all districts in the WC, and the four largest towns in the three districts are situated here. About half of this population falls under the low-income category and 13% of households are without income. The primary economic sector of this area is agricultural – in particular the production of wine. The Western Cape Province has the highest reported rate of FASD in the world and drug related crime is on the increase. Many of the children

[2] CSPID annual report March 2017, submitted to WCED

from this district have probably been affected by substance abuse and exposed to gang violence. There is also a high number of teenage pregnancies, but large-scale community initiatives exist to address these issues and their consequences [55].

The Cape West Coast is the largest of the three districts, spanning 31 000km². With a significant increase in the population (currently about half of the population in the Cape Winelands) and decreasing levels of water supply, this less resourced district is under immense pressure to address basic services. Manufacturing as well as agriculture and fisheries are the main economic sectors of the area, but a large part of the population is situated in remote areas. A disturbing reality is that half of all households in this district are without any income. Teenage pregnancies are above the average for the WC and the case load for tuberculosis and anti-retroviral treatment is on the rise [56].

The Overberg is the smallest of the three districts, having about one third of the population of the Winelands. Although almost two thirds of the population completed at least matric, crime and corruption (including substance abuse) affect some of the popular tourism destinations in the area. This has implications for employment opportunities and the district's already small economy is reported to be weakening. Affected by the migration of people to the WC Province, informal settlements are rapidly growing [57].

Only four of the 20 rural SCCs are situated in towns within 100 kilometres (km) from the special school where the team is based. Eleven are between 100-200 km away and five are situated more than 200 km from the Base School. These distances have huge implications for the way in which educational services were delivered in the rural settings of this study.

1.5 Structure of the thesis

The thesis consists of six chapters. The first presents the background and rationale, and describes the research setting. It contains the aims and objectives of the study.

Chapter 2 presents a literature review to inform and support this study. The outline of the review is done according to the Ecological Systems approach, which is explained in a short introduction. The account of what SPID entails (including the prevalence and aetiology) is followed by a portrayal of the impact that SPID has on the child, the family and society. International approaches and frameworks for support are explored, and a report given on the nature and content of interventions in the field of SPID used across the globe. Appropriate assessment tools are then explored and specific knowledge about the P scales are assembled. This chapter ends by exploring studies about factors related to educational performance in children with SPID.

The research components are presented in three parts, namely a description of the characteristics of the children (Chapter 3), the validation of the P scales as an appropriate assessment tool (Chapter 4) and, finally, using the P scales to investigate possible variables of educational performance of children with SPID (Chapter 5). Chapter 5 also gives a detailed account of the educational and

therapeutic support services delivered by the rural outreach team. The methodology, results and discussion are presented in each chapter that deals with the corresponding component of the research.

Chapter 6 concludes with a summary of the main findings and their interrelationship, the shortcomings of the study and the implications for the future in relation to policy, practice and research in the field of SPID.

Chapter 2. Literature review and theoretical frameworks

2.1 Introduction

A literature review was undertaken to inform the choices made in the study. In order to plan services, it is necessary to establish the number of children who would be in need of services for children with SPID. Therefore, this review starts with a discussion of the aetiology and prevalence rate of SPID in the WC and situates this prevalence nationally and internationally. In an attempt to address inequality in education [9, 58], a co-ordinated, multi-sectoral approach is advocated where current partnerships are strengthened and existing initiatives built upon [59]. The impact of SPID was examined through the lens of the Ecological Systems approach, discussed below. It is within this framework that existing literature is analysed, evaluated and results are synthesized.

In addition, information relating to the P scales and other instruments to monitor performance in children with SPID was sourced. This was done to determine if the choice of P scales as an outcome measure was justified and how best it should be validated.

2.2 Methodology

A narrative review was done of the available literature relating to the topic, using the databases and search terms as indicated in Table 1.

TABLE 1: LITERATURE SEARCH STRATEGY

Databases	**Search Terms**	**Results**
Intellectual disability (Chapters 3 and 5)		
Pubmed Cochrane Scopus Web of science CINAHL ERICA Psychinfo.	"intellectual disability" "profound intellectual disability" "inclusive education" "academic performance" "educational participation" "factors of change" "monitoring progress" "improvement"	57 relevant articles
P scale validation (Chapter 4		
Pubmed ERICA Psycinfo PsychTests	"performance scale" "inclusive education" "educational outcome" "special education" "special needs" "attainment targets"	25 relevant articles

Pearling was done and secondary sources were searched. This process was repeated until a point of saturation was reached at approximately 270 journal articles, books and thesis as well as about 38

other resources, which included government documents, web pages and reports. This process was followed throughout the period June 2016 to January 2018. A coding sheet was used to sort relevant articles according to the three chapters. The resources applicable to Chapter 3 were further sorted and guided according to the ecological systems approach. After evaluation of these resources, about 122 useful journal articles, books and theses were identified. Thirty six of the 38 supplementary resources were chosen. This process is represented in

Figure 1.

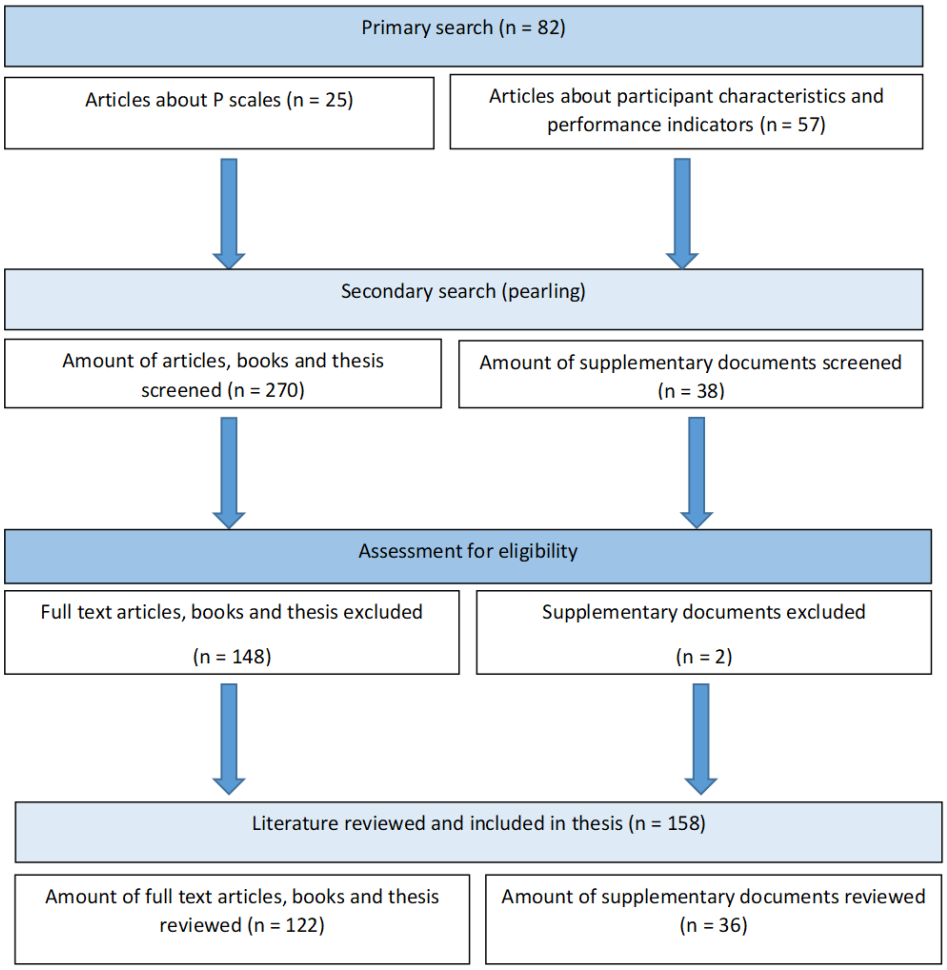


FIGURE 1: PROCESS FOLLOWED TO REVIEW THE LITERATURE

These were then critically analysed and results interpreted. Most of the existing literature on the characteristics of children with SPID and the services provided for them were from an international perspective. Very few articles were available on the P scales and none reported on academic attainment or educational performance of children with SPID. Available literature was synthesized to guide and justify the development and organisation of the study.

2.3 Results

2.3.1 [3]Definition, prevalence and aetiology of SPID

Intellectual disability is a disorder which begins in the developmental period and is diagnosed from the age of six years old, based on the adaptive functioning as well as the intelligence quotient (IQ) [25, 60]. Children with SPID demonstrate IQ scores of less than 35. Previously only the intellectual capacity was considered in the diagnosis and used to determine the severity of ID [61], which led to people being excluded from participation and denied essential services [11, 19]. Therefore, adaptive functioning is preferred when determining severity and planning services.

ID involves impairments of general mental abilities that affect adaptive functioning in three domains. According to the Diagnostic and Statistical Manual of Mental Disorders - 5th Edition (DSM 5) (P37), it is the conceptual (cognitive), social and practical domains of adaptive functioning, rather than IQ, that determine how well an individual with SPID copes with everyday tasks [25].

Individuals with SID and PID [4] demonstrate severe to extreme functioning deficits in all three domains (P36) [25].

In the conceptual domain, functional use of concrete objects may be acquired by individuals with PID, whereas those with SID have a limited understanding of basic symbolic concepts, for instance numbers and time.

Socially, the individual with PID may understand “simple instructions or gestures” (P36) [25] and express themselves through “nonverbal, non-symbolic communication” (P36) [25]. Although social activities are usually limited, they may “initiate and respond to social interactions” (P36) [25]. In the individual with SID, language is used socially, but they are limited in the ability to explain situations. Vocabulary and grammar are usually narrowed down to the present and in an ordinary context [25].

Practically, an individual with PID is fully dependent in terms of “daily physical care, health, and safety” (P36), yet able to participate in limited activities. They might be able to help with some domestic tasks. The individual with SID requires support and supervision for all activities of daily living, as well as safety. With continuous support, they can take part in domestic and recreational activities. They may acquire basic work skills with assistance, given that continuous and persistent training is done [25].

ID is considered chronic and is more often found in males – both globally [18] and in other rural parts of South Africa [62].

[3] Although the DSM-V defines the terms ‘PID’ and ‘SID’, the court judgement specified the target population as Severe to Profound ID.
[4] Although the DSM-V defines the terms ‘PID’ and ‘SID’, the court judgement specified the target population as Severe to Profound ID.

Furthermore, ID often co-occurs with other mental disorders such as depression [63], attention-deficit/hyperactivity disorder [64], and autism spectrum disorder [63, 65]. SPID is likely to be accompanied by an array of typically co-occurring health conditions, of which sensory impairments [20, 63, 66], epilepsy [24, 66, 67] and cerebral palsy [24] are most frequently found. General health problems [20] and psychiatric conditions [63] add to the complexity of this condition. As a result, 11 different terms for more severe forms of ID were identified in published literature. For the purpose of this study, the term 'severe to profound intellectual disability' is used, with the understanding that children with SPID may have complex and multiple disabilities, including limitations in their intellect as well as severe deficits in physical functions [20].

Globally the prevalence of ID is estimated to be about 1.04% and about 6% of those with ID fall within the spectrum of SPID. The highest rates of ID are reported in low and middle income countries [18]. Data from Africa is sketchy and outdated [18, 22], but prevalence in South Africa appears to be higher than the global average [24]. Globally higher prevalence rates are found in children than adults [18] and in South Africa it is even higher amongst children [62].

Many of the conditions that cause ID in South Africa are preventable, but a lack of reliable data sources renders few explicit figures [24]. Amongst a small sample of 238 children with ID in rural South Africa (2008), it was found that 6.35% were acquired and the cause was congenital in nature in 20.6%. In most cases, however, the cause remained undetermined [62].

Acquired causes of ID, can be attributed to biological, environmental and socio-economic factors. Alcohol-related conditions and the sequels to the misuse of alcohol, including injury and accidents, are prominent factors of the known preventable causes of SPID. Poverty and the cumulative result of inequality in education contribute to the prevalence of SPID through intra-uterine growth restriction, nutritional deficiencies and infectious diseases. [24, 68, 69].

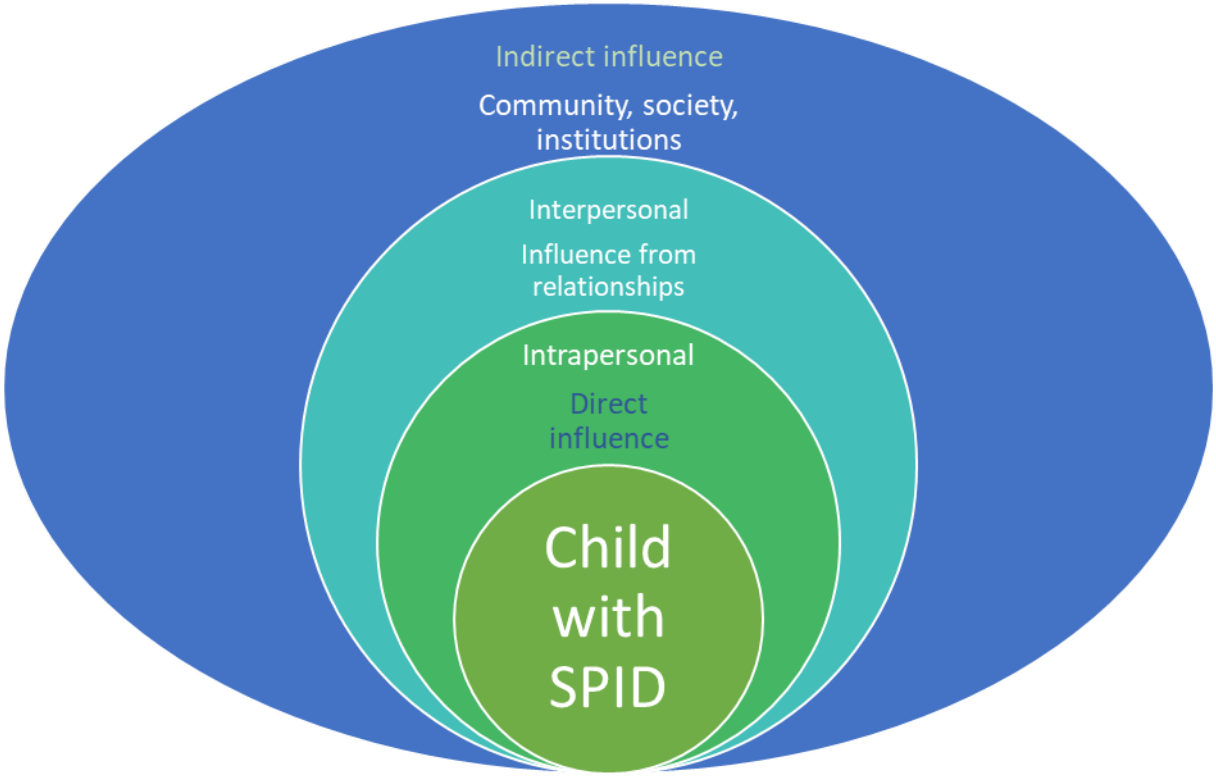
Children with ID experience a general delay in achieving expected milestones [25]. Where development is severely affected, it is known that it is not only one factor, but rather aggregated determinants that are at play. It is through cumulative exposure to numerous risk factors that brain structure and function are adversely compromised and consequently the "developmental trajectory" of the child is negatively influenced [68].

These factors have a dual impact on the child. Apart from the aetiology, it also highlights the complexities of the circumstances in which children with ID generally live and develop [24]. Although a small part of the total population, children with SPID constitute a very vulnerable group with complex support needs. They thus require a completely different approach in meeting their educational needs, most specific in terms of assessment. Mainstream examination and more traditional assessment batteries are not responsive enough to determine their performance.

2.3.2 Ecological systems approach to SPID

Documenting these complexities requires a systematic approach from an educational perspective. The Department of Basic Education (DBE) promotes an ecological systems approach, the national conceptual framework of Care and Support for Teaching and Learning [59]. This approach intends to

enhance understanding and address barriers to learning, thus creating an enabling environment with the child and his/her caregivers as the core entity. Factors that influence a child with SPID are represented in Figure 2:



(Adapted from the Department of Basic Education - Action step: National Model Care and Support for Teaching and Learning [59])

FIGURE 2: INFLUENCES ON THE CHILD WITH SPID FROM THE ECOLOGICAL SYSTEMS APPROACH PERSPECTIVE

This study acknowledges that there are multiple spheres - including school or SCC, the community at large, which includes non-governmental organisations (NGOs) and government departments, educational policies and service provision - directly influencing the child with SPID [29, 59]. It is within this framework, with the child as the core entity, that the findings from the literature review are structured.

2.3.2.1 Impact on the child

In order to define the characteristics of the child with SPID, it is necessary to be familiar with their demographic and medical profile as well as their functional and participation abilities. Having severe to profound neuro-motor dysfunctions leads to medical complications, which frequently require medication [20]. The demography of children with SPID, attending 16 SCCs in the WC metropole, were described to be a diversity of disabilities with wide-ranging levels of functioning, spread amongst children from a large age range [53].

The heterogeneous nature of children with SPID was confirmed in 10 SCCs in the WC in 2012. Associated health conditions found amongst children with SPID were the following: cerebral palsy (40%), visual impairment (9%), hearing impairment (3%), autism spectrum disorder (7%) and global developmental delay (11%) [36]. Fifteen percent reportedly had unspecified health conditions and the absence of accurate diagnosis is flagged. In addition, prevalence of epilepsy in SPID in rural WC was found to be 19.4% [44], higher than the national figure of 15.5% in ID in general [24]. The stark contrast to the much higher prevalence rate of epilepsy (more than 50% in PID in developed countries around the world) [66] suggests a different composition of co-morbid health conditions associated with SPID in South Africa and the WC [24, 44]. Comparison should, however, be done with great caution. In the absence of ICD codes, the Global Burden of Disease categories were advocated for the classification of *probable* co-morbid health conditions in the validation of this dataset of the provincial educational outreach team [44].

There is evidence in the literature that children with SPID frequently fall victim to sexual abuse perpetrators due to the limitations in functional abilities and learning [22, 70]. Although this study does not aim to document the extent thereof in the current study population, it is important to consider that this stark reality forms part of the contextual landscape of this already marginalized and vulnerable group of children.

Although most of the children with SPID in rural parts of the WC were described to have no means of independent mobility, were unable to handle objects and seldom able to effectively communicate their needs, large variations existed – also in terms of self-care abilities and educational performance. Attainment of learning outcomes were, however, not reported on by Spangenberg et al. [44] and no other documentation about the functioning of children with SPID in South Africa could be found.

The profile of the child with SPID in terms of functioning is unique to the individual, especially so in terms of communication [20]. Mainstream assessment of academic attainment is irrelevant. Even though not in typical manner, children with SPID have the ability to learn and apply knowledge [71, 72] and need to take part in activities which improve their quality of life despite their limited abilities [42, 73]. The interdependence of the different disabilities and developmental domains, however, requires a collaborative approach from many professionals in order to determine function and performance. On an international level, there is a need for “collaborative interdisciplinary observational methods”, but hardly any standardized instruments exist with which to do so [20].

2.3.2.2 Impact on families and societies

SPID not only affects the child, but their life long, constant high-intensity support across all life environments places a tremendous burden on families [19, 22, 62, 74]. The condition is accompanied by stigmatization and families are subject to discrimination within their communities, which leaves a family despondent and desperate [22]. Professionals, on the other hand, might perceive this despondent attitude as an environmental barrier to learning [75]. These factors could all prove to be confounding variables in the identification of factors influencing the child’s performance.

In the WC, children with SPID are still to a large extent not accepted at mainstream crèches nor accommodated in schools, rendering parents unable to earn an income [53]. This is the situation for many families, whose children are not enrolled in SCCs or included within the education system [36, 44]. A sample survey of the levels of living conditions amongst households confirmed a perpetuating cycle between poverty and disability in Southern Africa [17, 76]. The burden on the family is only partly relieved through a care dependency grant (CDG), provided for the care of a child with a severe disability in need of full time and specialized care [77]. There is a lack of reliable data with regards to the socio-economic situation of children with SPID within the NPO sector in the WC [44]. It can nevertheless be deduced that this population is "to be found amongst the poorest, most vulnerable and marginalized" [24] due to the inequalities of the past [9, 78].

2.3.2.3 Society's response

Equally important to consider is the context in terms of services, systems and policies. Available funding and resources ultimately influence the approach to assessment and intervention, as well as meeting the needs in terms of appliances and transport. The Department of Social Development (DSD) leads government services though a Provincial Framework for Persons with Intellectual Disabilities, which clarifies the roles between the different government departments in the WC.

The Department of Basic Education (DBE) in South Africa caters for diverse needs through mainstream, full service inclusive schools, special schools and specialist outreach services into the community [29]. *The Draft Policy for the Provision of Quality Education and Support for Children with Severe to Profound Intellectual Disability* includes a Learning Programme, which aims to facilitate "meaningful participation in education " [33, 34, 79].

McKenzie et al. (2017) provide a detailed narrative of how educational provision was made available in the WC. The Court judgement stated that the lack of state provision of funding for educational needs was to be addressed in collaboration with existing NGOs and SCCs. It became apparent that 15% of the children attending the 44 SCCs in 2012 had SID and it was suggested that they should rather attend a special school or unit class [36]. Other findings which contextualise the study population are the physical, attitudinal and supportive environments in which services are provided and learning has to take place.

Many SCCs were found to be "cramped and under resourced" facilities for large groups of children with diverse impairments who require "labour intensive basic physical care". Many of the caregivers were unpaid mothers or volunteers. The staff members, who received payment, were mostly underpaid [53]. Carers had additional roles like cooking and/or cleaning [36]. With high a child: staff ratio and hardly any resources [53], the focus was on physical care rather than educational stimulation [36]. Most care workers had no formal basic training [53] and many only an educational qualification of grade 10 [36].

In the WC it is unknown how many children receive instruction in their home language, but given that these centres are community based with large scale involvement of mothers it is expected that most would have access to a care worker speaking his/her mother tongue [36, 44, 53].

Before 2011, when therapy services were available through fundraising and NGO support, it was mainly in the form of assessment and focused on health and well-being rather than education. By 2014, in the rural areas, assistive device needs were largely met. In some instances, therapist involvement went beyond the scope of assessments. Contradictory contributions from therapists (from different government departments and different NGOs) could influence the way in which educational programs are implemented by the care workers. This could potentially affect the outcome of interventions [36, 44, 53].

At the commencement of this study, the rural outreach team supported 273 children in 12 SCCs spread across three educational districts. Support services were delivered before and whilst the Learning Program was being developed. Due to the aforementioned void in curricular content, international frameworks and approaches to intervention were explored, in order to compare and evaluate current intervention practice in the rural outreach team.

2.3.3 Strategies for the support of children with SPID

2.3.3.1 International frameworks for support

Through policies and conventions, it is universally accepted that inclusive education plays a vital role in addressing marginalization and exclusion of people with disabilities. Internationally, models were developed with respect to the constructs of (intellectual) disability, quality of life and supports that currently offer frameworks for guidance and integration of different disciplines in the field of ID services. Using frameworks ensures a multidimensional approach, leading to the delivery of comprehensive services and best practices which can be of value to an international audience [39].

One such framework, considered in the conceptualisation of this study, is the WHO International Classification of Function, Disability and Health - children and youth version [1]. This framework acknowledges the role of contextual factors, can assist to structure research methodology [39] and provides a norm in terms of terminology [80].

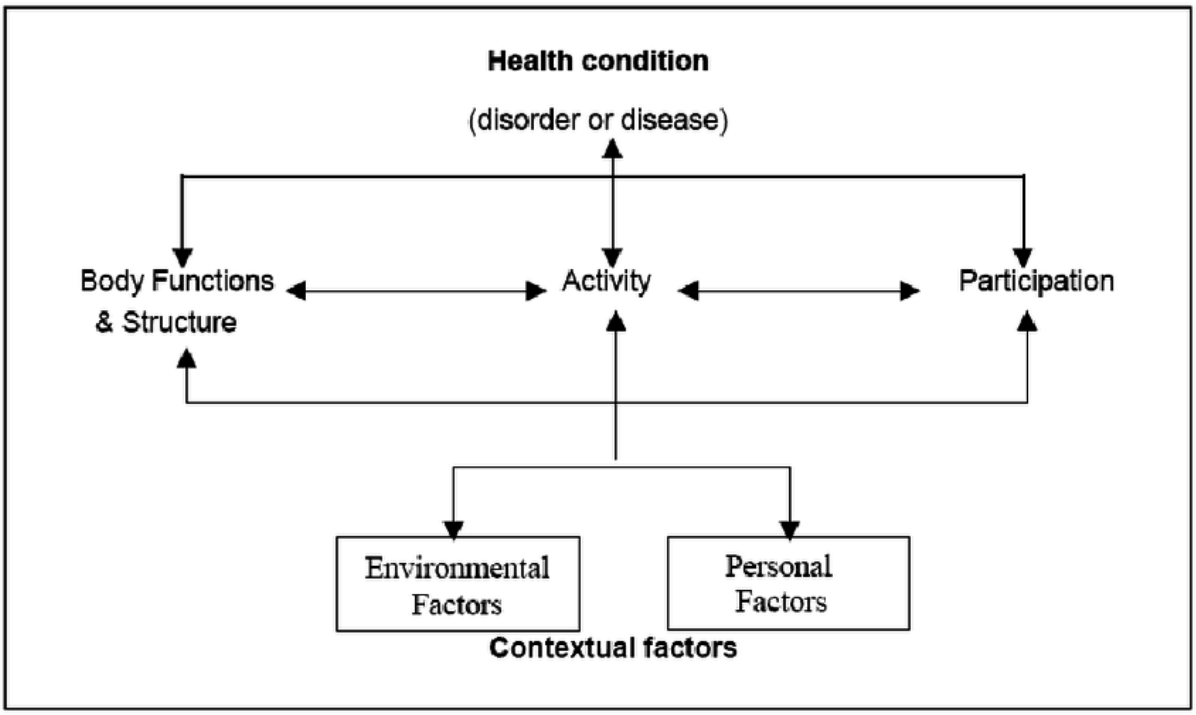


FIGURE 3: INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH [6]. COPIED FROM RESEARCHGATE [81].

The American Association on Intellectual and Developmental Disabilities (AAIDD) developed a conceptual framework of human functioning that presents ID as an interaction between intellect, adaptive behaviour, health, participation and context with a separate and central focus on the crucial aspect of support [39, 60, 82, 83]. Similar to the ICF, this very relevant theoretical model was used to ensure a holistic approach in setting up a study about the efficacy of using the P scales as a measure of educational performance.

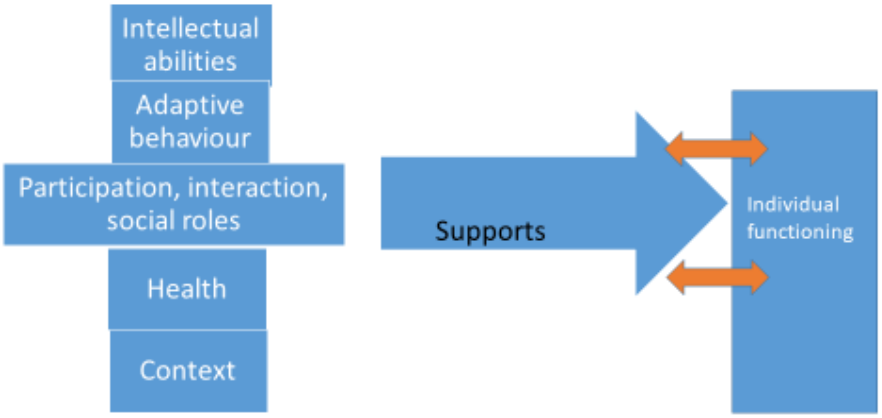


FIGURE 4: FRAMEWORK FOR SUPPORT (AMERICAN ASSOCIATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES)(P 286) [39]

Quality of Life (QOL) models value the present circumstances of the person with ID, merit a thorough description of the research participants and confirm the importance of including a participation-level monitoring tool into the educational database [39, 41, 82].

The support model acknowledges that the person with ID is an active part of his own development and reiterates that approaches to service delivery need to be person-centred and needs-based [31, 60, 84].

In parallel, all these models underpin the rationale for the measurement of impact on the level of the individual. Therefore, they were considered in conceptualising the constructs and methodology of this study. This was done to ensure meaningful research that hoped to enhance holistic service delivery in the field of SPID [39] in the WC.

2.3.3.2 International approaches to intervention

In order to contextualize assessment of educational performance and support in this study, it is necessary to look into international approaches. The draft framework for a therapeutic and educational stimulation programme[5] was compiled by the provincial outreach team themselves and operating procedures determined largely by the team itself. Neither Spangenberg et al. (2016) nor McKenzie et al. (2017), however, documented the nature, content and frequency of support to children and SCCs [36, 44].

Caution is needed where approaches from high-income countries are concerned, as it has been reported that some participants in studies in these countries had more than one assistant per child [85] – in stark contrast to the current context as described above.

In high-income countries, various approaches were identified. Initially programs were centred around normal child development, with sensory and environmental enrichment (including music) and continuous intensive repetitions. The aims were to create social interaction and development of language (Knill & Knill, 2008, as cited by Kontu & Pirttimaa, 2010) [86]. Gradually a more functional approach was incorporated. Teaching everyday skills of self-care, domestic tasks, use of money, language and communication were introduced. This was done with support from therapists to address specific disabilities. Eventually children with SPID could access the national curriculum of, for example, the United Kingdom (UK). This was made possible by setting guidelines for assessment, organising classrooms and adapting the curriculum [11].

Another functional approach to education was found in high-income countries, where instead of milestones a limited set of essential motor skills required for daily functional activities are trained. Emphasis is on frequent repetitions integrated into various aspects of the day in order for a trained skill to be generalised [87, 88]. Again, the combination and integration of therapy and educational

[5] Draft Framework for Therapeutic and Stimulation Programme: Children with severe to profound intellectual disability, developed by Provincial CSPID team November 2012, submitted to WCED

services were found to significantly influence independence by giving the child a chance to gain more control over his/her own life [26].

In the broader African context the content of intervention categories is still very much inclined towards health rehabilitation and limited educational input [89]. Therapeutic and other services to children with SPID are reported to be integrated with neither community based health nor education systems in Africa [21]. Yet the importance of parental and community based training programs by means of a multi-disciplinary approach has been acknowledged [21] and implemented in various low and middle income countries, including neighbouring Southern African countries [38]. Research in South Africa shows that there are challenges in accessing community health services and that professionals need to acknowledge and use the skills of people with disability and their family members [90].

Through international frameworks it is apparent that any approach to intervention should be person-centred and needs-based, with repeated individual assessments a prerequisite of support at the level of service provision [19]. Activities of daily living should be a key focus and stimulation programs needs to be adapted according to the assistance required, taking into account the need for constant supervision and care [91]. The key to successful service delivery, however, lies as much in the approach to the intervention as in its implementation [41].

2.3.3.3 Content, nature and frequency of intervention

The content of support to children with SPID in the WC was not documented before [36, 44]. Neither did literature from around the globe, whether educational, developmental or therapeutic, give detailed accounts of what exactly intervention in children with SPID entails. According to Darrah et al. (2011), descriptions of specific interventions are the least explored part of intervention studies in rehabilitation in general and remains a challenge in establishing the efficacy of intervention, even when the literature search was expanded to include CP [92-94]. Very little research has been done on comprehensive regimes used in daily practice, again even within the field of CP [95]. With the exception of communication training, content of interventions found in the literature were mostly limited to high-income countries and the effectivity determined for only a few. What is evident, however, is that training programs should be multi-faceted with a problem-solving approach and integrated into existing practices [41] at the SCC.

Components of intervention and methods of implementation need to address the “fundamental learning processes” which takes place in children with SPID [71]. These children learn through a process of habituation, association, repetition, observation and imitation [71, 96]. In 2002 the AAIDD model was used to very relevantly describe how alertness and attention, structure and routine as well as integrated activities form the basis for learning in SPID [96].

The behavioural state of the child, namely alertness and attention [97], is determined not only by the physical health of the child with PID, but also by the environment in which learning takes place. By creating an environment that optimizes a child’s involvement, as well as the amount and quality of interactions, care staff are the facilitators of learning [98]. When there is engagement between the child with SPID and the environment during suitable and meaningful activities within an

organised and structured routine, skills development can take place [73, 99]. At the same time, engagement in appropriate activities has been shown to decrease problem behaviour [100].

Children with SPIDs' perception of the environment is mostly oriented at their own body and they need direct support to create an awareness of their surroundings (Frolich, 1995, as cited in Petry, 2007) [96]. Social "connectedness" between care worker and child, as well as the willingness to include them in games and activities, determines their participation in daily activities [41, 53, 101]. Increased sensitivity and responsivity of care workers and parents to non-verbal cues of children with SPID should be prioritized as a way to create a "responsive environment". Changes made to the environment could result in more opportunities for the child to communicate, which in turn would result in improved social interaction [41]. Thus, in general, in children with similar levels of impairment, changing the environment can have a positive impact on participation of the child with SPID [102]. This is also the crux of an inclusive approach to education – "changing the environment rather than the child" [11].

Programs and care worker training need to include individual and group activities with a prevailing element of fun [41]. Both the amount and the quality of support should be addressed [41, 99, 101] in order to create engagement in choice-making opportunities, which could in turn result in improved behaviour [103]. Training care workers to create communication opportunities and increase the amount of competent communication partners, during all activities of the day, requires 'buy-in' from care workers [53, 104]. Practical onsite and hands on training of group activities to enhance communication were shown to have the best chance of being sustainable in the context of SCCs in the WC [53]. It has been derived that the complexity of SPID in a context of poverty and a difficulty to access services (including assistive devices) necessitate a focus on basic communication [75] as opposed to technologically aided Alternative and augmentative communication (AAC) [104, 105].

Multisensory activities lead to increased levels of alertness and interaction with persons and objects [41]. One such activity is multisensory storytelling. The aim is to maintain attention and optimize engagement through repetition and the way in which the story is designed and the stimuli presented. In order to maintain attention, innovation is required from a storyteller who adheres to guidelines, who is sensitive to signs of attentiveness and able to offer alternative stimuli [106]. Regular implementation by care workers and close monitoring by the team are required to ensure successful execution.

Activities of physical care fill the bulk of the day and a time when individual attention is required [73]. During care activities, choice-making opportunities can be structured [41]. Knowledge about the child, accumulated through direct one-on-one interaction can translate into understanding subtle cues of the individual and result in an improved ability to accommodate the individual's needs within a group. Children can also learn the sequence of a self-care routine through observing their peers [107] and these activities in itself can be considered a theme for the design of meaningful activities [41, 73].

Children with SPID rely on their support to be able to execute motor tasks. Context and task modification are thus crucial to ensure optimal participation [107] and resultant motor learning to take place in children with SPID [88]. Task specific training should happen in the child's "natural

environment for retention of skills trained" and integrated into daily life [87]. The focus of intervention can be on enhancing participation through their actual daily performance of say, walking, irrespective of their capacity to walk [108]. This would, in turn, probably improve his/her activity performance to bring it in line with his/her capacity to do so [109].

Assistive devices play a role in preventing limitations through maintaining a good posture and compensating for limited motor abilities - essential to inclusion and participation [107, 110, 111]. A good posture is crucial as an enabler of the social-communicative interface [112], while freedom of movements of the head, arms and hands is a prerequisite for learning through taking part in relevant activities – all elements which improve psychosocial wellbeing [113, 114]. Posture support devices need to be tailor-made, however, and require trained professionals to deliver, train and monitor services [115].

In order to increase the independence of the child, it is necessary to integrate therapy and education into all aspects of the daily program and activities should be deliverable by all support staff [26, 94]. Involvement of parents and carers is crucial to optimal skills development across different environments for children with SPID [88].

A number of international studies investigated context-specific constraints in terms of implementation, including management structures, the alignment of programs with aspirations of care centres as well as staff attitudes [40, 41]. It should be expected that changes will be made to programs and the dynamics of implementation should be considered in relation to numerous factors, instead of single determinants [40].

This means optimal implementation of programs requires a high frequency of support. Irrespective of the approach to intervention, content of programs or nature and frequency of support, personal outcomes should be documented as part of individualized support [39], and the complex interaction effect of contextual constraints should be taken into consideration [40]. Once again, this indicates that the impact of service delivery should be measured through rigorous use of standardised outcome measures [38].

2.3.4 Monitoring the impact of educational support to children with SPID

Assessing abilities, support needs and especially learning in SPID is no easy task, as each child presents with a unique set of functional limitations [20]. As a result, there is a lack of assessment instruments which not only measure one construct, but take into account the relations between different disabilities within different developmental domains [96, 116]. According to Forsyth (2007), a measurement of participation is needed to evaluate the delivery of support services [117], but presents a definite challenge especially in children [118]. Participation is a multidimensional construct described as "involvement in a life situation" by the WHO ICF-CY. In research, through the selection of classes, characteristics of participants and assessment measures can be standardised. In this context, the focus is specifically on the major life area of education (d839), which is best covered by the ICF domains of learning and applying knowledge (d110-d199), general tasks and demands (d210-d299), communication (d310-d399), mobility (d410-469) and interpersonal interactions and

relationships (d710-d729) [1]. Even more difficult to represent in research is the construct of performance [4], which is essentially what is measured when academic attainment is determined.

Structured observations are frequently used in this field, but it is urged that these observations should be collaborative and interdisciplinary in nature in order to have a holistic understanding of the child with SPID [20]. Since interaction and engagement with the environment are required for learning to take place [119], initiation of interaction and active choice-making should form a core component of such an assessment tool [97]. Due to the fact that children with SPID express themselves by using body language consisting of subtle signals [120], the assessors' knowledge of the children can in fact lead to more accurate interpretation thereof [121]. This means that the care worker and/or family member should be consulted and observation lists completed in collaboration with educationalists.

Equally important is the fact that assessment should be a continuous and dynamic process of revising outcomes [91]. Populating the educational data base with repeated assessment outcomes will allow for the quantification of the nature and functional impact of SPID in the children serviced by the specialized teams [44]. In turn, this can assist to address the poor understanding of the nature of services required for children with SPID, as reiterated by McKenzie et al. [36].

One aim of this study was to validate the suggested tool for the measurement of educational performance, the P scales, within the current context. The P scales, which are the national curriculum performance attainment targets for children with special education needs in the UK, were included in the educational database for children with SPID in the WC [44]. This measure of educational oriented achievement was considered a "way of recording, reporting and building on progress, however small" [11].

An exhaustive review of outcome measures is beyond the scope of this review, as many of the measures were identified and piloted at the time that the database was developed for use by the WCED team. However, discussion of all the measures incorporated into the database and used to validate the P scales is presented below.

2.3.4.1 Classification systems

As found during the development of the database, the classification systems were accessible for use by all team members and the routine use of them was possible in the context of service delivery in the WC [44]. The Gross Motor Classification System was used to determine the level of mobility. It is classified into five levels; level one represents the least amount of physical disability and level five the most. Age bands are used to accommodate for the natural development of the child. Bodkin et al. (2003) evaluated aspects of reliability and validity and found an interrater reliability of 0.84 when extending the use of the GMFCS to children with Down Syndrome [45]. This extended reliability and validity of the GMFCS (supporting its use in clinical practice and research) is of particular interest for this study.

The Manual Ability Classification System was applied to establish the level of fine motor control. Validity of the MACS was established and has excellent reliability of 0.97 between therapists and 0.96 between parents and therapists [46].

The Communication Function Classification System (CFCS) indicates the communication ability of the child. The interrater reliability of the CFCS was 0.66 between two professionals. The test–retest reliability was 0.82 [47].

These classification systems were included to give a gross measurement of the level of activity according to the ICF Framework [124]. They were not used to measure change, as it was not developed with the purpose of measuring difference over time or subsequent to intervention [145]. They were rather used as predictor variables and for validation of the P scales.

2.3.4.2 Vineland Adaptive Behaviour Scales II

Similar to the classification systems, the use of the Vineland Adaptive Behaviour Scales II (VABS II) was advocated for by the research task team of WCED [44], but not yet included in the database. As a measure of change in adaptive functioning, the Vineland Adapted Behaviour Scale, developed by Sparrow, Balla & Cicchetti in 1984 [48], was Identified as an outcome measure that includes the majority of measurable indicators of change in SPID. It comprehensively assesses skills in four domains. namely: motor skills, daily living skills, communicative skills and social behavioural skills. Although in the severe and profound levels of functioning, the Adapted Behaviour Scale survey form did not perform as well, the reliability of the instrument was found to be good in the total study population and the subgroups of children and adolescents with ID [49]. High construct validity was found in all groups and in the specific levels of functioning (n=826, age 4–18 years) [49]. It has been used as a co-indicator of the level of intellectual functioning in, amongst others, a collaborative international study, including South Africa, on Foetal alcohol spectrum disorder (FASD) in 2009 [122] and specifically in Cape Town on learning disability in 2005 [123]. The internal validity of the VABS was found to be sound in the South African context, as it was not language specific, but culturally sensitive and relevant [124]. It was therefore chosen as an outcome measure with which to establish concurrent validity of the P scales.

2.3.4.3 P scales as measurement of attainment

The use of the P scales - developed in the UK in a fully inclusive education system [11] - to assess educational performance in children with SPID in community centres in the WC were piloted (but not validated) by the rural team in 2014 [44]. Limited subject areas were implemented and the favourable outcome warranted further investigation.

Teachers in the UK arrive at a given P scale score in consultation with parents, therapists and various other role players. A continuous process of moderation takes place, from school up to a regional level [2]. The results are also fed into a national system through the Centre for Evaluation and Monitoring at Durham University and analysis thereof found that the P scales are valid and efficient in differentiating the curriculum [51].

Based on the Rasch Model of Crohnbach (1971) and the item response theory of Messick (1995), the P scales were found to meet the following criteria: “a holistic combination of the content, the substantive meaning of the test, the structural nature, its generalisability and its external and consequential validity”[51] .

In terms of validity, the ratings “discriminate the levels”, indicating that there is a progressive increase in complexity and it shows the difference between higher and lower functioning learners. This study also found that the level scored approximately the same across subject areas. Yet in higher functioning learners, it allowed for better discrimination between the curricular areas. This was found to happen because of experienced assessors and a process of moderation - which was found to improve the objectivity. It allows for adaptations according to different categories of learning difficulties [51], rendering this assessment tool very relevant for the heterogeneous nature of SPID. This was accepted by the South African education authorities, who drew upon the P scales in the development of the draft Learning Programme for children with SPID. Face and content validity of the P scales were therefore accepted for the purposes of this study.

Currently it is accepted that children with SPID can progress, in the sense that the amount of support needed to participate in daily activities can be reduced. This is done by addressing skills geared towards a growing sense of independence [39]. The P scales address both activity and support across a wide range of subject areas [125], incorporating both curricular content and adaptive behaviour.

In order to establish concurrent validity of the P scales, the VABS II were chosen, as a reliable measure of adaptive functioning and valid in the South African context [48, 49, 126]. Stipulated in the DSM-5, adaptive functioning specifies the severity of intellectual disability and in turn indicates the level of support needs [25, 39].

The classification systems give a gross measurement of the level of functional and physical ability of a child (ICF Framework) [127]. Classified into five levels, level one represents the least amount of physical disability and level five the most [46]. Levels could be clustered and known groups of children with similar functional abilities in terms of mobility, hand function and communication can be formed in order to establish known group validity of the P scales [45-47].

Given the consultative nature of allocating P scale scores, internal consistency would be the indicator of choice in terms of reliability [51, 128]. As an ordinal scale, Chronbach’s alpha were found to be the preferred statistical method to determine internal consistency [128].

Lastly, it is necessary to look at the interpretability and external validity of this assessment tool [128]. This could be done through consultation with experienced professionals, who have used the 2009 version of the P scale level descriptors [125] in the wider population of the WC [44] and rating their responses in terms of the feasibility and accessibility of the P scales.

2.3.5 Indicators of educational performance – explored by means of multivariate models

Many research studies, investigating associations with or determinants of capabilities and performance, used the ICF as the conceptual framework in laying out the constructs under investigation [95, 102, 117, 129]. Both the concepts of activities and participation, according to the ICF-CY, can be defined by the constructs of capacity (what a child can do in a standardized environment), capability (what a child can do in a daily environment) and performance (what a child does do in a daily environment) [5]. The construct under investigation, which guided assessment of the literature, is that of the course of performance. Academic attainment for children with SPID can be seen as reaching the next level of performance according to an ordinal scale named P scales. Furthermore, through the ICF framework, it is known that environmental factors affect the participation of young children with severe disabilities about as much as do intrinsic determinants [92, 117, 130].

In children with SPID in the WC, these factors are particularly multifaceted and from multiple spheres [36, 44]. Comprehensive rehabilitation outcomes research has recently been advocated as a means to illustrate associations affecting outcomes in the midst of multifactorial challenges. In using this approach, the results are expected to be of significance on the level of service delivery. The problem is, most studies which considered multiple variables in relation to participation in children with disabilities in general, were largely concentrated around cerebral palsy [117] and very little evidence exists from studies with such inclusive proportions [95].

Results from the literature reviewed show that different factors are associated with different domains of daily living [95, 131] and therefore studies about which factors bring about change in performance of children with SPID should ideally consider multiple factors in doing so [95]. Apart from the challenge in the measurement of participation, Forsyth et al. (2007) identified the difficulty of unidimensional measurement of the effects of impairment related to a myriad of childhood morbidities. He advocated the exploration of the compounded effect of multiple impairments [117].

Unfortunately, no studies were found where the P scales were used as an assessment tool to explore factors involved in the performance of children. Only one study, which dealt with indicators of educational performance in children with Down Syndrome, was identified [132]. This study investigated academic attainment in children with intellectual disability in the UK. The intellectual impairment itself was found to be the main predicting factor in the attainment of educational outcomes, with considerable variation in scores for children with severe intellectual disability and no change in scores for children with IQs under 20 [132].

It is only possible to identify factors associated with an increased chance of improvement by documenting the intervention strategies and resultant outcomes from measures of functioning and performance. In order to do so, the following were found to be important when documenting intervention to determine evidence of best practices [43]:

- Setting
- Interventionist
- Methods of implementation
- Treatment intensity and duration
- Components of intervention

It seems then that, in this void of research in this field, the information gained from multivariate models, which examine environmental factors together with those from other dimensions [133], could best inform daily practice [131]. Longitudinal studies which take into account the heterogeneous nature of the health condition, the activities, the course of performance (learning) as well as other possible determinants are needed - not only in CP [131], but also in SPID. Accurate documentation of intervention is the key to an optimal outcome.

2.4 Conclusions of the review

As the result of extreme functioning deficits in the conceptual, social and practical domains, as well as a variety of co-morbid health and medical conditions, children with SPID are in constant need of care and support. Establishing the number of children with SPID in need of services is the foundation from which to plan services. Equally so is the nature of the support needs of the child with SPID.

Although it is known that most of the conditions causing SPID are preventable, the aetiology remains mostly unknown. Poverty and the cumulative result of inequality in education contribute to the prevalence of SPID.

Irrespective of the high support needs of this population, which place a tremendous burden on the family, and despite the stigmatization and discrimination they face within their own communities, these children have the right to education. Providing services to children with SPID places a burden on government systems with limited resources, yet they have the right to development and quality of life. Consequently many challenges remain, despite initiatives taken by the state departments following the High Court judgement [31]. One such challenge is the inclusion of children with SPID into the schooling system - therefore most remain within SCCs.

It is known that more than half of the estimated 3000 children with SPID are accommodated in care centres around the WC[6]. SCC facilities are not all licenced and well-equipped facilities. Many carers are volunteers or receive stipends only.

Intergovernmental collaboration initiatives led to a more holistic approach in addressing the situation after 2010. Inclusive education outreach teams were appointed by WCED who followed a phased approach to service delivery according to the affidavit as set out by the court. These teams

[6] CSPID annual report March 2017, submitted to WCED

faced enormous challenges, yet two papers were published in collaboration with the University of Cape Town, because of the fact that the teams documented the groundwork they have done.

The validation of an educational database for children with SPID in the WC can now be utilised to determine whether the P scales will be a valid outcome measure with which to assess learning in the current population. Documentation and comparison of the characteristics of this study population to what is known about children with SPID in general determines the external validity of the study. Through repetitive measures of the P scales, the course of children's performance within education can be determined. Factors identified through searching the literature could be used to explore the value of the P scales as a relevant tool in research.

This is an entire new field and very few studies were to have investigated the factors related to learning in SPID. It was therefore necessary to look for pointers from studies done on children with CP. It became apparent that these factors should include both intrinsic and environmental aspects and studied through the lens of multidimensional models in order to be of clinical significance.

In order to validate an outcome measure with which to do so in the context of children with SPID, this study commence by describing the characteristics of the children who attend SCCs in rural parts of the WC and report on other services they receive (excluding WCED support).

Chapter 3. The characteristics of and services received by children with SPID in rural SCCs

As highlighted in the literature review, there is a dearth of knowledge regarding the impact of SPID on the functioning of children. There was also little information found regarding the characteristics of the recipients of the services from the educational outreach teams. Demographic and epidemiological information will assist in providing appropriate services in the future. The objectives of this section of the study are to describe the characteristics and needs of the children currently receiving services from the rural outreach team in terms of:

- Demographic and medical characteristics
- Functional ability using Gross Motor Function Classification System, Communication Function Classification System & Manual Ability Classification System
- Ability to participate in structured activities using P scales
- Met and unmet needs for appliances and transport

3.1 Methodology

A retrospective record review design was used and data were gathered from the validated database for children with SPID in the rural districts of the WC.

3.1.1 Participants

The inclusion criteria for this section of the research included admission to one of the 20 SCCs spread across three of the four rural educational districts in the WC between 1 September 2014 and 31 March 2017. The children needed to be younger than 18 years on admission and be diagnosed with ID for their data to be included. Their information had to have been entered on the WCED database.

There were 501 children who were admitted to these SCCs, but three did not have ID and their data were excluded. The final sample thus consisted of 498 children of which 367 were still enrolled and younger than 18 years of age at the time of data collection. Parental consent was obtained for inclusion of the data of all children.

3.1.2 Instrumentation and measurements

The database of the rural outreach team of the WCED was the primary source of data. The structure and content of the database had been finalized through focus group discussion and consensus building and registered with the Human Research Ethics Committee of the University of Cape Town (HREC REF: 109/2016). The database included questions related to demographic and impairment related information, socio-economic data, medical information and the need for appliances and transport support. Demographic information was collected by rural team members from individual files kept at SCCs, as well as through discussion with centre staff. A data collection form was filled out manually by one of the five team members of the rural team. The fields in this data collection form, which is in routine use by the rural team, correspond to the items in the database.

Piloting of the database was carried out by team members and the results published in September 2016 [44].

Appendix A represents the data extraction form. Minor changes from the published database were made both to response options and to ensure a logical order of questions. These changes were necessary to optimize the process of data entry and to include outcome options not previously considered. Item 32 - Therapeutic intervention (non CSPID)[44] - was split into items 33 and 34, in order to distinguish between therapists from the Department of Health versus other (non WCED) therapists. Items 36-38 were added in order to indicate when a child did not have ID. Items 39-46 were added to include VABS II scores (Chapter 4) and item 65 was added to give account for those who left the centre. CSPID interventions (described in Chapter 5) were expanded into items 66-71. The added items and response options were piloted on 22 children from one SCC.

The outcome measures included in the database are described below.

3.1.2.1 Function classification systems

The classification systems (Appendices B1-3) were included to give a gross measurement of the level of activity according to the ICF Framework [127]. Classified into five levels, level one represents the least amount of physical disability and level five the most [46].

The Gross Motor Classification System was used to determine the level of mobility [45], the Manual Ability Classification System was applied to establish the level of fine motor control [46] and the Communication Function Classification System (CFCS) indicates the communication ability of the child [47]. Also see 2.5.

3.1.2.2 P scales

As an educational outcome measure the P scales (P scales, Appendix C) were used [125]. These attainment scales are differentiated performance criteria and give an idea of the child's level of participation in structured activities throughout the day, hence measuring educational oriented achievement. The P scales use eight performance levels to illustrate learning. Levels P1 to P3 show the earliest levels of general attainment. Levels P4 to P8 show subject-related attainment focusing on extending understanding and connecting knowledge. The extracts from the P scale level descriptions 2009 for English (Communication), Physical Education and Mathematics in tables C1-3 will assist in understanding the value and relevance of this tool [125].

Rather than using all the P scales, the most useful subject areas were identified and implemented by the rural team. Three subject areas were chosen to align with the subject areas in the draft Learning Programme for learners with SPID, which was developed by Department of Basic Education [33, 34]. English - Speaking and Listening was chosen to cover the home language and/or method of alternative communication and not one specific, preselected Language. Mathematics was limited to Using and Applying Mathematics and Physical Education was chosen as an additional skill, also part of the Curriculum Assessment Policy Statement (CAPS) Life Skills curriculum [134]. No adaptations

were made to the instrument, but selected subsections were used. This was done in order to enable the use of this outcome measure within logistical constraints of service delivery in the current context [44].

The therapists that administered the P scales received no formal training in terms of the procedure when allocating scores. A process of moderation was followed, within the rural team, to uniformly apply P scales (Appendices C1-3), where all five team members discussed and agreed on the participation abilities of some of the children (who were the first to be assessed). Ongoing discussions were held about Issues related to the scoring procedure, both in the rural team and during three focused discussions of the provincial team in 2014 (two) and 2016 (one) respectively. A validation study, as described in chapter 4, was conducted in 2017 to establish reliability, validity and sensitivity of selected subject areas of the P scales in the present context.

3.1.3 Procedure

The registered database (HREC REF: 109/2016) was submitted again as part of the application for ethical approval from the University of Cape Town's Faculty of Sciences Human Research Ethics Commission for this study. Ethical clearance to conduct this study was obtained in November 2016 (HREC REF: 634/2016) and permission to conduct the study was granted from the WCED Directorate: Research. Written consent from parents/guardians has been obtained annually as part of routine service delivery practice (Appendix F). The consent related to routine assessment and research involving routinely collected information. The WCFID, other non-profitable organisations, as well as management of the specific SCCs, were informed of the study.

The routinely collected available data were not in electronic format. Not all information was readily available or up to date (at the time of data entry). Therefore, information obtained from the parent, centre staff or the individual files kept at the centre, was added during the process of data entry, where necessary. After administration of the standardized instruments, results were added to this data collection form, kept in the offices of the rural team. The data were readily available to the researcher, who formed part of the outreach team. The data were entered into a survey instrument application, Magpi [135] and imported to an Excel spreadsheet for the purposes of this study. Checks were not made by an impartial party to ensure that information was correctly entered. However, the data were cleaned and checked for any apparent incorrect entries and these were then corrected by returning to the source documents.

The files created during statistical analysis were saved in cyber space on Dropbox [136], where the information was shared with the supervisor. No other person had access to this Dropbox folder. It was also backed up manually upon creation of these files by Statistica [137].

Manual back-up copies of the archival sets were labelled and stored in a locked cupboard in the office of the researcher at the special school where the rural team is based. These records will be retained and destroyed according to the regulations as stipulated in the Caldicott Report on patient confidentiality and the main principles of the Data Protection Act of 1998. Care will also be taken to ensure adherence to Act No. 4 of 2013: Protection of Personal Information Act, 2013.

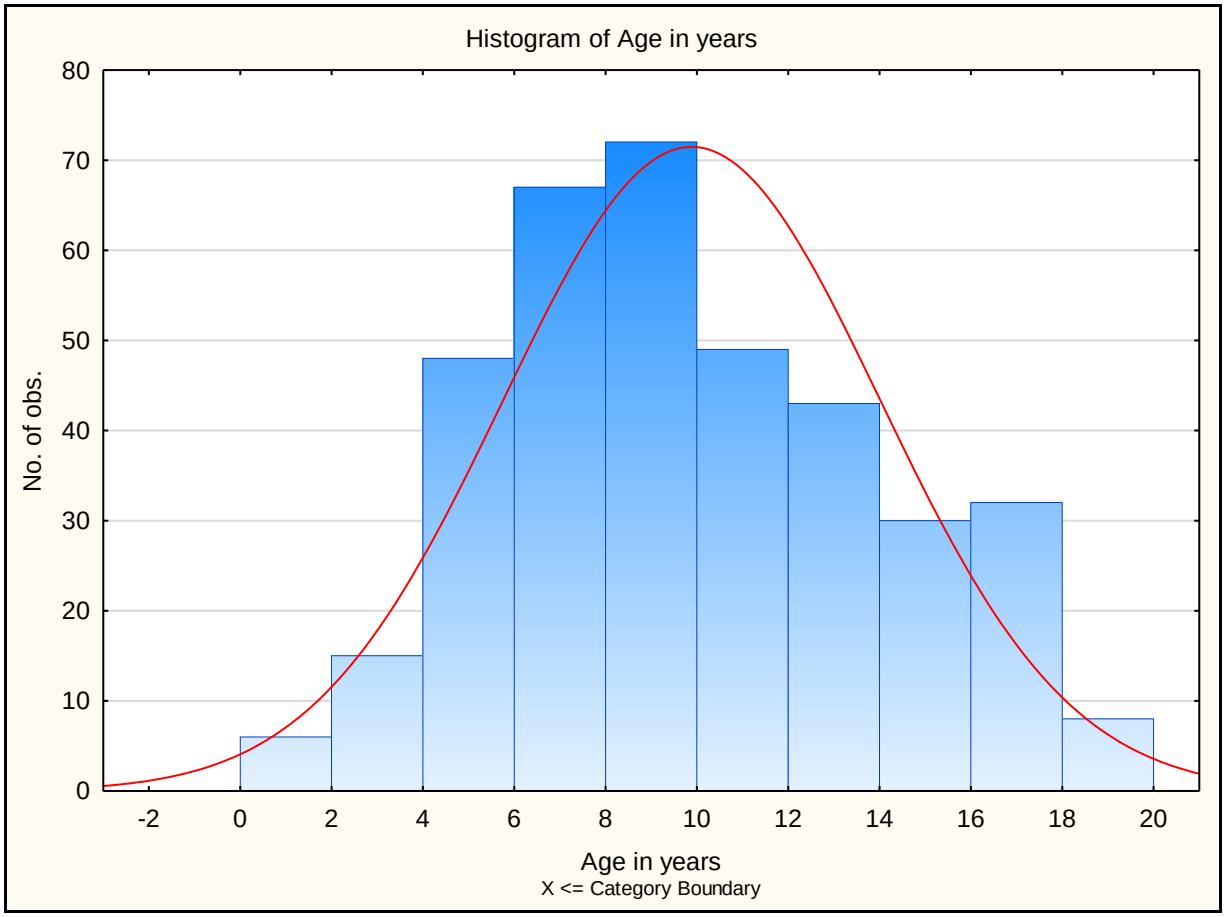
3.1.4 Data analysis

Descriptive statistics were employed in describing the characteristics of the children involved in this study.

3.2 Results

3.2.1 Demographic details

Of the 498 children with ID (representing 20 centres in 17 towns), 293 (58.8%) attended in the Winelands Educational District, 123 (24.7%) in the Overberg Educational District and 82 (16.5%) in the West Coast Educational District between September 2014 and March 2017. There were more males (297 or 59.6%) than females (201 or 40.4%) and of the 370 children attending SCCs on 31 March 2017, the mean age was 9.9 years (SD=4.1, range 1.2-19.6) with the youngest being one and the eldest being 19 years of age. This smaller sample, to determine the mean age, consisted of those children who attended at that given point in time – as children moved in and out of the SCCs during the course of the study. The histogram below indicates that the majority of children were between the ages of four and 16 years of age (Figure 5) with the greatest frequency between 6.1 and 10 years of age.



n= 370 attending centres in March 2017.

FIGURE 5: HISTOGRAM OF AGES OF CHILDREN

The home language of 68.1% of the study population was Afrikaans, followed by IsiXhosa (28.1%). (Table 2). The majority of children (80.7%) received instruction in their home language.

TABLE 2: HOME LANGUAGE

Language	No. of children	Percentage
Afrikaans	339	68.1
Xhosa	140	28.1
Sotho	8	1.7
English	5	1.0
Other African	3	0.6
Tsonga	2	0.4
French	1	0.2

n=498

The largest number of participants (33.7%) lived with single parents, with 146 (29.3%) residing with both parents (Table 3).

TABLE 3: FAMILY STRUCTURE

Family structure	No. of children	Percent
Single parent	168	33.7
Both parents	146	29.3
Foster care	66	13.3
Unknown	66	13.3
Extended family	35	7.0
Orphans	17	3.4

n=498

In 94.6% of cases (471) there was no information related to income of parents/guardians available.

Information on social grants were also largely unavailable. This was the case in 310 (62.2%) of the participants. Of the remaining participants, 81 (16.3%) were in receipt of a care dependency grant and 46 were in the care of the state (Table 4).

TABLE 4: SOCIAL GRANTS

Type of social grant	No. of children	% of children
No information	310	62.2
Care dependency	81	16.3
Care of state	46	9.2
Child support	22	4.4
Foster care	17	3.4
None	17	3.4
Foster and care dependency	5	1.0

n=498

3.2.2 Health conditions and medical intervention

As only 5.6% of children had a specific diagnosis (ICD-11) indicated in their folders, the majority of the most probable health condition/s (as indicators of co-morbidity) were based on the therapist's knowledge of the child and the information (provided by guardians) in the centre folders (Table 5). The same was true about chronic medical conditions (Table 9). Cerebral palsy (28%) and idiopathic ID (13.3%) were the most common probable health conditions.

TABLE 5: PROBABLE HEALTH CONDITIONS

Health condition	**Count**	**Percent**
Cerebral palsy	139	27.9
Idiopathic intellectual disability	66	13.3
Childhood behavioural disorders	49	9.8
Epilepsy	49	9.8
Down's syndrome	37	7.4
Alcohol use disorders	34	6.8
Other neurological disorders	29	5.8
Acquired brain damage	28	5.6
Unknown	14	2.8
Other congenital anomalies	12	2.4
Sense organ disease of eyes	10	2.0
Other chromosomal anomalies	8	1.6
Other musculoskeletal diseases	7	1.4
Neural tube defects	6	1.2
Hearing loss	5	1.0
Spinal cord injury	2	0.4
Other medical conditions	2	0.4
Unipolar depressive disorders	1	0.2

n=498

Sixty percent had no co-morbid health condition reported, and epilepsy was present in 11.2 % of the children (Table 6).

TABLE 6: PROBABLE CO-MORBID HEALTH CONDITIONS

Co-morbid health conditions	No. of children	% of children
No co-morbid conditions	295	59.2
Epilepsy	56	11.2
Vision loss	48	9.6
Childhood behavioural disorders	32	6.4
Other neurological conditions	31	6.2
Hearing loss	12	2.4
Other musculoskeletal diseases	6	1.2
Alcohol use disorders	6	1.2
Acquired brain damage	5	1.0
Other congenital anomalies	2	0.4
Other mental and behavioural disorders	2	0.4
Drug use disorders	1	0.2
Other sense organ disorders	1	0.2
Cleft lip and cleft palate	1	0.2
Total	498	100

n=498

Two hundred and ninety-five children had only a single health condition indicated in their folders. The combined frequencies of probable health conditions can be seen in Table 7.

TABLE 7: PROBABLE HEALTH CONDITIONS

Health condition	No. of children with condition
Cerebral palsy	139
Epilepsy	105
Childhood behavioural disorders	81
Idiopathic intellectual disability	66
Other neurological disorders	60
Alcohol use disorders	40
Down's syndrome	37
Acquired brain damage	33
Hearing loss	17
Other congenital anomalies	14
Unknown	14
Other musculoskeletal diseases	13
Vision loss	10
Other chromosomal anomalies	8
Neural tube defects	6
Other medical conditions	2
Spinal cord injury	2
Other mental and behavioural disorders	2
Unipolar depressive disorders	1
Cleft lip and cleft palate	1
Drug use disorders	1
Total conditions	652

n=498 children

The aetiologies, derived from the Global Burden of Disease [138], of the most probable associated health condition can be seen in Table 8. The categories of maternal and child conditions and congenital and hereditary conditions accounted for more than half of all aetiological causes.

TABLE 8: AETIOLOGY OF PROBABLE HEALTH CONDITIONS

Aetiology	No. of children	Percent
Maternal and child	135	27.1
Congenital and hereditary	127	25.5
Mental and behavioural	45	9.0
Hydrocephalus	43	8.6
Unknown	38	7.6
Substance abuse	38	7.6
Infectious and parasitic	30	6.0
Neurological	18	3.6
Sense organ disease	12	2.4
Trauma unintentional	5	1.0
Neoplasms	2	0.4
Nutritional deficiencies	2	0.4
Other	2	0.4
Trauma intentional	1	0.2
Total	498	100

n=498

There were few probable chronic medical conditions identified, with respiratory infections (6.0%) and digestive disease (5.2%) being the most common (Table 9).

TABLE 9: PROBABLE CHRONIC MEDICAL CONDITION

Chronic medical conditions	No. of children	Percent
Respiratory infections	30	6.0
Digestive disease	26	5.2
Oral conditions	15	3.0
Cardiovascular disease	14	2.8
Skin diseases	12	2.4
Genitourinary disease	12	2.4
Tuberculosis	10	2.0
HIV affected	9	1.8
Endocrine. blood and immune disorders	5	1.0
Otitis media	2	0.4
Diabetes mellitus	1	0.2
Neoplasms	1	0.2
None indicated	356	71.5
Total	498	100

n=498

TABLE 10: MEDICATION CATEGORY

Medication category	No. of children	% of children
Anti-convulsion only	72	14.5
Chronic medical	32	6.4
Psychiatric	27	5.4
Multiple (3+)	23	4.6
Anti-spasmodic	18	3.6
Anti-convulsion and anti-spasmodic	6	1.2
Anti-convulsion and psychiatric	6	1.2
Bladder control	1	0.2
None/missing information	313	62.9
Total	498	100

n=498

More than one third (37%) received chronic medication, the most common of which was anti-convulsion medication, alone or in combination with other drugs (16.9%) (Table 10).

Surgical intervention (type unspecified) had been undergone by 11 (2.2%) of the children.

3.2.3 Provision of services, including aids and appliances

One hundred and ten (22.1%) children received therapeutic assessments and input from the DOH which were mainly for the purposes of allocation and distribution of assistive devices (Table 11).

TABLE 11: AVAILABILITY OF ASSISTIVE DEVICES (WHEELCHAIRS, BUGGIES, SPLINTS AND STANDING FRAMES)

	Yes	Yes, but needs new	No	No, but needs to use	Uses centre equipment
Wheelchair	64	3	417	5	*
Buggy	104	ł	383	7	*
Splints	42	2	426	6	*
Standing frame	3	ł	409	19	35

Ł, The need for standing frames were not assessed
*, Wheelchairs, buggies and splints are issued according to the specific needs of the client

Tests for hearing and vision were not performed, but based on the folders and 16 children needed spectacles, five needed hearing aids and three needed alternative augmentative communication (AAC).

TABLE 12: PROVISION OF TRANSPORT

	Count	Percent
Centre	360	72.3
Public paid centre	47	9.4
Resident in centre	41	8.2
Private	12	2.4
Public	12	2.4
Barrier	11	2.2
Private paid centre	11	2.2
Unknown	4	0.8
Total	498	100

n=498

Most of the centres provided transport to the children (Table 12). This was the case for 360 (72.3%) children. Where centre transport was unavailable, public transport was utilised for 47 children, private for 11 children and then paid by the centre. Transport was regarded as a primary barrier for 11 children. In four of the cases, centre transport was not utilised, but it was unknown whether public or private transport was used.

Apart from the children who received in-centre therapeutic input from DoH, other therapeutic services available at SCCs were from students, volunteers or therapists paid by an NGO (partly funded by DSD).

Overall exposure to therapeutic services received from both DoH and the NGO sector (including student therapists) can be seen in Table 13. Almost half of the children were treated by a multidisciplinary team (47.6), with speech therapy as the next most common therapy provided (11.0%).

TABLE 13: COMBINED RESULTS ON THERAPEUTIC SERVICES

Nature of therapeutic service	Count	Percent
Multi-disciplinary	237	47.6
Speech therapy	55	11.0
Occupational therapy	29	5.8
Assistive devices only	27	5.4
Physiotherapy	18	3.6
None	102	20.5
Unknown	30	6.0
Total	498	100

n=498

Other stimulation activities presented by volunteers or NGOs can be seen in Table 14 below. These services were available to the minority of children, with 330 (66.3%) children who did not receive such services. The most frequent type was activity ideas tailored around a toolkit, which was available to 72 children. Fifty-four children enjoyed horse riding and thirty-two children had access to more than one type of stimulation activity over and above those followed in the daily routine of the SCC.

TABLE 14: OTHER (NON-THERAPEUTIC) SERVICES AVAILABLE

Other services	No. of children	Percent of children
None	330	66.3
Toy kit and activities ideas	72	14.5
Horse riding	54	10.8
Swimming	24	4.8
Horse riding as well as a movement and sport based program	8	1.6
Unknown	5	1.0
Movement and sport skills based program	5	1.0
Total	498	100

n=498

Of the 132 children who left the centre, 43 went home and 40 were transferred to schools. Fifteen died, nine were included in ECD centres and 16 left due to relocation. For the rest, the reason remains unknown (Table 15).

TABLE 15: OUTCOME OF CHILDREN ON 31.03.2017

Outcome on 31.3.2017	No. of children	Percent
In centre*	359	72.1
At home	43	8.6
Special school	22	4.4
Mainstream school	18	3.6
Relocated to other town	16	3.2
Deceased	15	3.0
Unknown	9	1.8
ECD inclusion	9	1.8
Relocated to other SCC	4	0.8
Temporarily out of centre	3	0.6

**Relocation to other rural SCCs and ECD inclusion within the same facility is the reason for the difference between 370 children supported, as registered at the specific date of 31.3.2017 and the number of attendees presented as "in centre" in this table (n=498).*

3.2.4 Classification systems

The use of the classification systems was extended and used for children with any given health condition. As can be seen in Figure 6, peaks are observed at the highest level (Level I) and lowest level of functioning (Level V), with the exception of manual ability, which also showed a peak at mild deficit in hand function (Level II). The highest peak according to the GMFCS and MACS occurred at Level I, whereas the highest peak for communicative abilities was found at Level V.

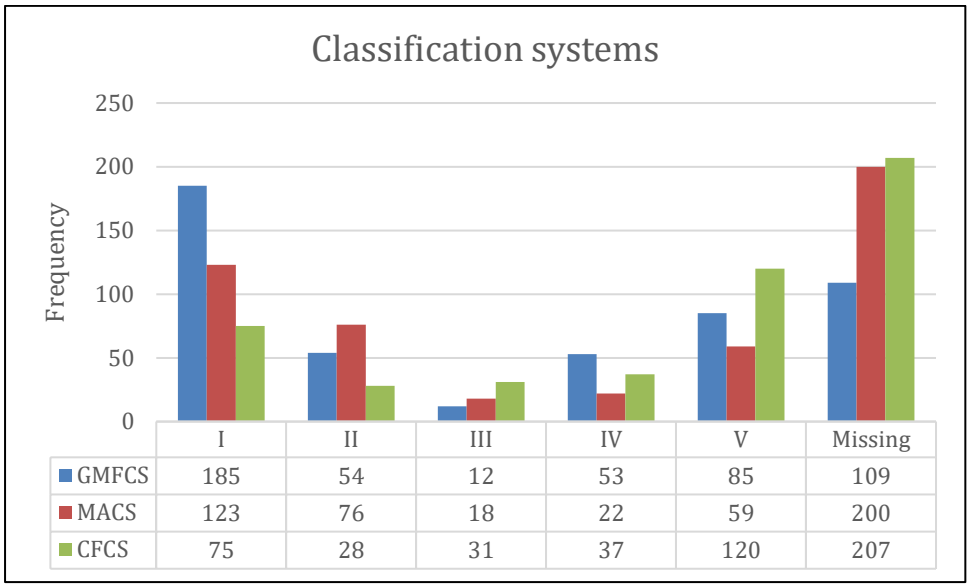


FIGURE 6: FUNCTIONAL ABILITIES (GROSS MOTOR, MANUAL AND COMMUNICATION)

The GMFCS was applied to 389 children and 239 (61%) of them were able to mobilise independently (Level I-II). The remainder were mobile with an assistive device (Levels III-IV). Of the 298 children assessed using the MACS, 199 (67%) were able to handle objects independently, including those with limitations in quality and speed of achievement (Levels I-II) Of the 291 children assessed on the CFCS, 134 (46%) were able to communicate effectively, including those with slower paced communicative abilities, but the others had inconsistent communication (Levels III-IV).

3.2.5 Support needs for self-care

The amount of support needed for self-care activities as indicated on their individual support plan (ISP) for the second assessment is summarised in Table 16. Information was largely unavailable (417, 83.7%). Forty needed maximal support while 12 were reported to be independent in the execution of self-care tasks. The remaining 29 needed either supervision or minimal or moderate support.

Of the 42 children who were assessed using VABS II, the age equivalent for personal living skills ranged between less than one month and 8.5 years, with a mode of 0.7 years and a mean age of 2.46 years (n=42; SD=1.86) (See Chapter 4).

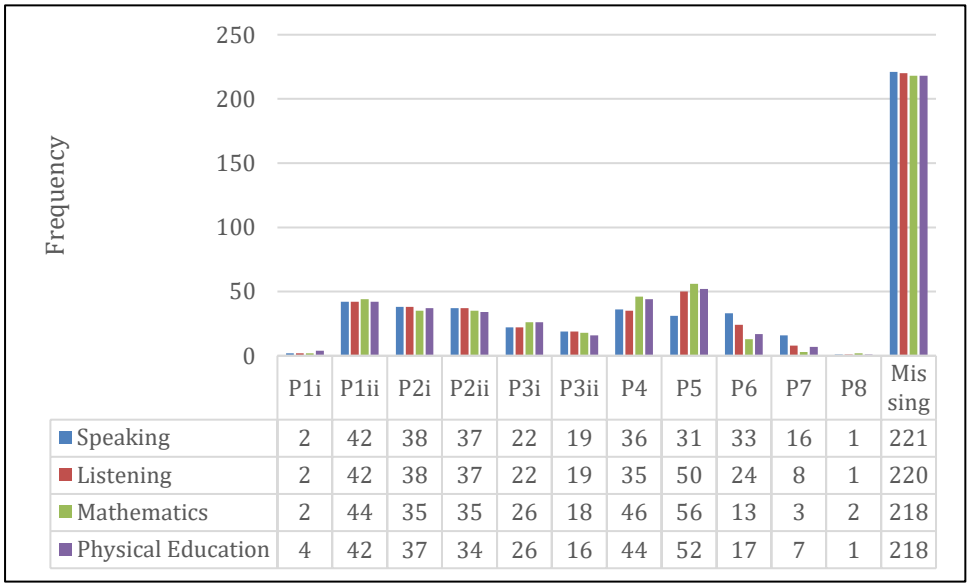
TABLE 16: SUPPORT NEEDS FOR SELF-CARE ACTIVITIES

Degree of support	Frequency	%
Maximal	40	8.0
Moderate	13	2.6
Minimal	9	1.8
Supervision	7	1.4
Independent	12	2.4
Missing	417	83.7
Total	498	100.0

n=498

3.2.6 P scales

As can be seen in Figure 7, in all subjects there were very few children in the extreme categories of low and high performance. Most children fell between the P1ii and P2ii or between the P4-P5 levels.



	P1i	P1ii	P2i	P2ii	P3i	P3ii	P4	P5	P6	P7	P8	Missing
Speaking	2	42	38	37	22	19	36	31	33	16	1	221
Listening	2	42	38	37	22	19	35	50	24	8	1	220
Mathematics	2	44	35	35	26	18	46	56	13	3	2	218
Physical Education	4	42	37	34	26	16	44	52	17	7	1	218

Speaking n=277, Listening n=278, Mathematics n=280, Physical Education n=280

FIGURE 7: FREQUENCY OF COMBINED P SCALE SCORES

3.2.7 *Summary of results*

In summary, the majority of the 498 children came from the Cape Winelands District, with a mean age of 9.9 years and SPID predominantly found in males. Afrikaans was found to be the home language for most (68%) followed by IsiXhosa (28%). About one third of the children had a single parent (33%), about another third lived with both parents (29%) and a high number of children were in foster care (13%). Information on income and social grants was largely unavailable.

The most prevalent (probable) co-morbid health conditions were found to be cerebral palsy (27.9%), idiopathic ID (13.3%) and childhood behavioural disorder (9.8%). Almost half (40.8%) presented with more than one associated health condition, many involving cerebral palsy and epilepsy. Most prominent aetiological factors where regarded to be maternal and child (25%) or congenital and hereditary (23%) conditions. Thirty-seven percent of children were chronically medicated, but information on other medical and surgical procedures was largely unavailable.

Most children (62%) received therapeutic services from DoH, most for the purposes of assistive device allocation. The need in terms of wheelchairs and buggies was largely met, but despite the fact that many centres had standing frames, many children still did not have access to one. Other therapeutic services were rendered by NGOs, students and volunteers, with the effect that at least 74% had access to therapeutic input other than what was provided by WCED.

Transport was largely available through the SCCs, with only about 5% paying for private or public transport and for only 2% was transport considered to be a factor in poor attendance. Of the children who left the SCC, 30.3% were placed at a school, but 32.6% left only to stay at home.

In terms of functioning abilities, the highest peak according to the GMFCS and MACS occurred at Level I, whereas the highest peak for communicative abilities was found at Level V. For all subject areas measured by the P scales, peaks were observed at P1(ii) and between P5 and P4.

3.3 Discussion

The ecological systems approach, used to structure this discussion, relates the child and his/her characteristics and health conditions to the family composition, the community support and institutional support structures.

The objectives of this section were achieved and information, which may be used to inform service planning, was gathered. However, the sample is not necessarily representative of all children with SPID. According to the annual report on the services of the rural team[7], there are children from a number of centres, community outreaches or those on a waiting list, who did not form part of this study. In addition, as described in the literature review, there are estimated to be about 3000

[7] CSPID annual report March 2017, submitted to WCED

children with SPID in the province [36, 139, 140], of which approximately 17% are receiving educational support services from the WCED rural team.

3.3.1 Personal characteristics of the children

The predominant prevalence of SPID in males is as would be expected in a South African population [62]. The results of this study show a much higher ratio than the international male-to-female ratio of 0.4 to 1.0 in children with ID in general [18]. In terms of gender, the study population then mirrors the rest of South Africa's statistics in persons with SPID, but most likely not the situation in the rest of the world. This phenomenon may be a reflection of a combination of factors. In general, more males than female babies are born in South Africa [141]. Also, those genetic disorders which involve chromosome X usually affect more males [142]. The difference then probably lies in the unique composition of aetiological factors involved in persons with SPID in South Africa. However, ID affects both males and females to a similar extent due to societies' concept of disability and gender identity – often a source of discrimination against persons with ID and their families [143].

The distribution of age groups is an important parameter in terms of planning appropriate activities and activity material. The distribution of age groups indicates that the majority of activities can be designed towards the needs of the age group 6-14 years. The substantial number of children in need of early intervention (0-6 years) as well as those who need to access programs that address the unique needs of the adolescent, however, necessitate definite curriculum differentiation strategies. As the study participants in Chapter 5 were between the age of five and 16 years, it would be important to explore whether the content of intervention also catered for the needs of the adolescent.

Cerebral palsy and epilepsy were the most common neurological conditions associated with SPID, correlating to what Adnams et al. reported in 2010 [24]. This is of concern, as access to prenatal screening and genetic counselling [24] might have reduced this number. The finding that children with ID and ADHD had higher rates of oppositional defiant disorder [64], the relationship between ID and ASD [65] and the comorbidity of ADHD and ID with FASD [122] could most likely be the explanation for the high prevalence of childhood behavioural disorders in this study population. Early identification and the management of challenging behaviour should thus form a crucial part of parent and care worker training. With a structured day and a classroom environment conducive to optimal learning – where the specific needs of these children are met – it may be possible to reduce the impact of these disorders on children's behaviour [100].

Close collaboration with DoH in terms of accessibility to health records is identified as a prerequisite for future studies, as the information available at the SCCs was mostly lacking, similarly to the situation in 2014 [44]. Apart from the lack of accurate diagnosis, there were a large amount of missing data pertaining to medication and therapeutic services. It is not possible to state with certainty that the sample is representative of the population of children with SPID in the area, but the gender distribution and the causes (birth injury and congenital disorders) are likely to be similar. The information gathered from the records could thus be useful in planning and extending services to increase coverage. Findings from these records - from a public health, educational and social service perspective - are highly significant, especially in an increasing population. The burden of SPID

to society, to provide adequate services over time, becomes tremendous [18]. Apart from educational services, the burden arises from mental health issues, stigma and physical illness. Other than providing education, it would be advisable to utilise resources towards the prevention of ID [18]. According to the aetiological factors found in this study, like in other low-to-middle income countries, the focus should be on pre- and post-natal care [18].

About 40% of this study population had multiple probable health conditions associated with ID, and epilepsy was present in 21% of children. As seen in the results, several of these conditions may require ongoing medication. It is important, then, that care staff are trained in monitoring the administration of the required medication and that each SCC has direct access to medical personnel, should the need arise. Side-effects of medication and its consequences include behaviour changes and change in levels of alertness [66], with resultant impact on learning. It is imperative to control for the influence this variable could have on a child's performance.

Considering the detrimental effect on general health of children living in households where there is reported hunger and a prevalence rate of 18.2% for HIV in pregnant women in South Africa [27], the possibility exists that medical conditions are underrepresented in this study. International literature also reports high prevalence of associated medical conditions in children with SPID [66]. Absence but also limited participation in activities can be due to medical conditions, hospitalisation or surgical intervention. Therefore, it is imperative that support staff are aware of and trained to accommodate for the individual support needs due to chronic illness. It is also important to have accurate medical records in order to investigate the effect of medical conditions on educational performance.

The characteristics of the children in terms of their functional abilities are key to determine content of activities and to inform appropriate differentiation strategies in order to result in successful program implementation. Although more children had independent mobility and were able to manipulate objects successfully, the large number of children unable to do so necessitates training of all support staff on strategies to adapt activities for the child with physical disabilities. This means that individual input is required, at least for these children to participate effectively. In turn, a higher staff: child ratio is needed to acquire optimal participation. However, with 17% of children having limited to no voluntarily control of their movement, merely adapting activities designed for the mobile might not sufficiently address the unique needs of this group. For this group, it is important to consider whether activities were specifically designed to meet their needs or not.

A most important consideration is that less than half of these children are able to communicate their needs effectively. Very definite communication training of support staff, including professionals in outreach teams, is necessary to ensure they all become competent communication partners, who can provide opportunities to participate throughout all activities.

Comparing the statistical analysis of a large group with PIMD in the British study [51] to the results of this study, there seems to be less of an even distribution in P scale scores in the local context. It is worth noting that a large number of children, in this study, scored between P1 ii and P2 ii (where participation varied from merely being aware of immediate surroundings to responding to actions). In this group, another spike is seen at the P4 and P5 level, where basic subject and content related

skills are developing [125]. This might implicate the need for very definite differentiation strategies in order to ensure that optimal learning takes place, especially for the child with most profound ID.

The distribution and corresponding P scale level descriptors for Mathematics showed that the functioning deficits of this population correspond to what are described under the conceptual domain in the DSM-5 [25]. Similarly, the P scale descriptors for English Speaking and Listening correspond to the deficits in the social domain [25]. The dependence on others for self-care tasks has been described for a limited number of participants, but also show similarities to deficits in the practical domain, according to the DSM-5 [25].

3.3.2 Family situation

The larger part of the sample were likely to be from the lower socio-economic stratum of society, although there was little information relating to income in the records. This is further evidenced by results on family structure, in which only 30% were living with both parents.

The picture of the socio-economic complexities surrounding the child with SPID is bleak. Where about half of the children in the WC live with both their parents [27], less than one third of the known cases in this study had both parents involved. If a child from this study population is staying with parents, it is more likely that it would be with a single parent – a comparable statistic to the rest of the children in the WC. However, the burden of taking care of a child with SPID is evident in the fact that only about two thirds of known cases in this study population are staying with either one or both parents. This is in stark contrast to the about 88% of the general child population in the WC who do live with either one or both parents [27]. Sensitivity to both child and parents' circumstances is key to ensuring family involvement in implementing individual support strategies, an important factor in learning for the child with SPID [144]. It also means that prevention strategies and awareness campaigns about the aetiology of SPID should be aimed at the extended family and communities at large. Related information about other populations of children with SPID were not found in the literature, neither in South Africa nor abroad.

Although information on family income was very scarce in this study, according to the 2007 community survey, service providers should take into account that a child with a disability in South Africa is more likely to live in an informal settlement. This implies overcrowded living conditions, probably with lower access to water and sanitation than for children without disabilities [28]. Professionals who develop home programs will have to consider the probable lack of resources and utilise everyday objects or recyclable material.

According to Higgs (2007), money is the single most important factor in determining quality of life in the income category below R3000 per month [145]. In this income category, the lack of money has an enormous effect on especially the health and well-being of families and is amplified by the added burden of caring for a child with a disability [17]. Higgs (2007) also found that a most important factor in determining well-being was employment versus unemployment and determined that subjective well-being levelled off at about R7000 [145]. It can be argued, then, that it is most important to know whether a family has no income, little income directly affecting health, income to

the extent where health and subjective well-being levels off, or income above that. Should research in this field consider income category to be a factor to explore, it is suggested that categories be adjusted according to those used in Census 2011 to enable comparison. Alternatively, including information on employment might be almost as meaningful as income category, should this information be more readily available.

Information on the receipt of social grants was still largely unavailable, although findings showed improved access to information when compared to the subgroup of this study population used by Spangenberg et al. (2016) [44]. Although on a national level the uptake of CDGs cannot be computed due to lack of data on who needs or does not need permanent care [28], the results are an indication that the children in this study population are generally in receipt of social support in the form of grants. In accordance with the ecological systems approach, there is a need for SCC staff to ensure families are aware of and apply for CDGs.

The foster grant was initially, and still is to a great extent, intended as financial support for children removed from their families and placed in foster care for protection in situations of abuse or neglect [27]. It is highly possible then that some children in this study population have been exposed to severe forms of abuse and/or neglect. Both SCC staff and outreach team members need to work in close collaboration with social welfare officers. The safety of these children is crucial in order for optimal learning to take place. Only when their safety is being monitored and reported on will we fulfil our statutory duty as a citizen, a professional and as government department.

3.3.3 Facility and community services

From the literature review it emerged that care workers are volunteers, mothers or staff members, of which many are underpaid [53] and many without formal basic training [53] in either childhood education or home based care (with a medical approach). Yet the expectations are that these care workers receive training on medical related issues (such as diagnosis, first aid, medication) as well as basic principles of implementing rehabilitation and educational programs, without accreditation and the possibility of building a career pathway [36]. From the prevalence of health conditions found in this study, it is important for the care worker to understand at least the following: SPID, physical disability (mostly CP), epilepsy and childhood behavioural disorders (which include ADHD and ASD). WCED programs thus need to address all of these training needs, yet the possibility of facing an unwillingness to participate is real. The attitudinal environment is extremely important to consider and building relationships with staff a priority for outreach teams.

With regard to the services provided within the facilities, rehabilitation was not restricted to individual therapy. The fact that almost three quarters of the study population had access to therapists (in addition to WCED therapists) and that in most instances it was multi-disciplinary in nature, is a positive indicator in terms of service delivery to this group of children with SPID who attend SCCs in rural parts of the WC. Although this study did not report on assistive devices for walking, there was efficient provision of most other positioning and mobility devices. The added implication is that SCC staff also need training on the use and maintenance of assistive devices. However, according to 2011 statistics, the ratio of public service physiotherapists to the WC population (per 100 000) is 3.14 and occupational therapists 3.7 [28] which means that this study

population probably had more access to therapeutic services than other children with SPID in the WC [19, 24, 27]. As rehabilitation professionals fall under the 'scarce skills' category, the sustainability hereof is questioned. In order to provide evidence for the need of rehabilitation, refined documentation of the extent of therapists' involvement is advised.

The involvement of therapists, other than outreach team members, also necessitates close collaboration - both on an operational level and through inter-sectoral departmental meetings. This is necessary to prevent duplication of services and role confusion, but has implications for the frequency of centre visits by the outreach team.

Transport to children admitted to a SCC was mostly available, yet a high number of children left the centre only to stay at home. A large number of children were more suitably placed in schools or ECD facilities, but required follow-up support. This had implications for the outreach team, who then supported children in the community and collaborated with relevant schools, in addition to supporting the growing number of SCCs [8]. Another factor to consider was the inequality in the number of children and centres between the three districts. The time and distances travelled in order to deliver services to the various locations could have influenced equality in support to all SCCs and ultimately have affected the outcome of this study.

Not all children had access to instruction in their home language. Furthermore, assessment results show that definite age groups and distinct groups in terms of functional abilities and the ability to learn and apply knowledge exist. This has direct implications for the nature and content of educational support.

3.3.4 Strengths and limitations of the study

The distribution of P scale scores, as well as the dependence on others for self-care tasks described in this study, showed that the functioning deficits of this population correspond to what is described in the DSM-5 [25]. It can be deduced, then, that the study population is representative of the larger community of children with SPID in this regard, which would contribute towards the external validity of the findings from this study.

This part of the study also highlighted the importance of record keeping in identifying possible factors at play in the educational performance of children with SPID. The information gained add to the knowledge about the larger context of this study population. Although an appropriate design for the purposes of this study, retrospective record review has the challenge of incomplete records, as was the case in this study. The reason was that support services to this population was still novel and all the items were not mandatory to fill in all the items. An encompassing view of all the results can contribute to an improved estimate of the actual burden of this disability. Extrapolation of relevant findings can inform service delivery, both on a micro- and a meso-systems level in the WC, and parallels drawn to the rest of the country.

[8] CSPID annual report March 2017, submitted to WCED

The availability of information on age groups as well as functional and learning abilities provide guidelines for the development of content and structure of intervention strategies. It can also direct recordkeeping in relation to the nature and content of support.

Confounding variables were identified, like the underrepresentation of medical conditions or the access to therapeutic services and transport, which could have influenced the results depicted in Chapter 5. The fact that official diagnosis and medical records were mostly unavailable also hindered comparison in terms of prevalence and aetiology, which weakens the epidemiological value of this study.

Although data entries were double-checked and apparent incorrect entries addressed by returning to source documents, a sample of the entries was not checked by an impartial person. This poses a threat to the validity of the findings.

3.3.5 Recommendations

Collaboratively, departments and other role-players need to put measures in place to make information available to outreach teams. SCCs could be encouraged to ensure background information is captured comprehensively and to include income category and employment status to admission forms.

The P scale scores indicated that there were two groups of children, those with very limited performance (P1) and those with more educational ability (P4, P5) and, as their support needs are likely to be different, this should be factored into the training of support staff and the programmes offered.

Should the VABS II not be used as part of routine assessments in future, there is an urgent need for the development and validation of an assessment tool for support needs in terms of self-care. The process of validating an outcome measure with which to measure participation in structured activities for children with SPID is described in the next chapter.

Chapter 4. Validation of P scales

4.1 Introduction

As the major purpose of the WCED outreach teams is to provide educational and not only rehabilitation support to children with SPID, the identification and validation of a measure to monitor learning rather than functioning was very important. The P scales were identified as a good candidate measure, but it was not clear how they would perform in the WC context. It was thus necessary to validate the scales and to ensure that their use was feasible within the current context. The validation study of the P scales was undertaken by testing the constructs as outlined in the COSMIN (Consensus-based Standards for the Selection of Health Measurement Instruments) guidelines [128]. This checklist was developed to evaluate the qualities of studies about measurement constructs. This model considers reliability, validity and responsiveness to be key domains to address in validating an assessment tool [128].

Content and face validity were not re-examined as the scales had been used extensively and research done in the UK [51] and their use had been endorsed at joint meetings by experts in DBE.

The aim of this chapter is thus to establish whether the P scales is a psychometrically sound outcome measure within this context by determining the:

- Reliability as determined by the internal consistency (Cronbach's alpha).
- Responsiveness by determining the effect size of the change in scores over a period of at least one year.
- Known group validity through examining the difference in scores between known groups.
- Concurrent validity through examining the correlations between the Vineland Adaptive Behaviour Scales II and the scores on the relevant section of the P scales
- Feasibility and acceptability through consultation with a panel of experts who had used the scales.

The reliability and concurrent validity were established through cross sectional descriptive, analytical studies. The internal consistency and the responsiveness were examined post-hoc using the existing database through cross-sectional and longitudinal analysis.

4.2 Methodology

4.2.1 Participants

4.2.1.1 Validation studies

Children between the ages of 5 and 16 years were eligible for participation, as these are the recommended age limits for the use of the P scales. There were three sub-samples of convenience drawn from the children registered on the database.

The children in the sample used to explore the reliability and responsiveness of the P scales in this sample had to have their P scale score assessed routinely at two time points at least one year apart. They were drawn from all 12 centres, in Winelands and West Coast, where the P scales had been

administered twice. The P scales yield ordinal data and hence non-parametric tests were used. To test responsiveness, it was expected that there would be a small to medium change over one year. The sample size for a Wilcoxon signed ranks test was calculated using an effect size of .4 (small to medium[9]) [146], a p value of .05 and a power value of 95% [147]. A minimum sample of 73 children was required using these parameters (Statistica sample size calculation) [137]. One of the 84 children who had two scores did not meet the inclusion criteria, which rendered a sample of 83.

The second sample consisted of children who had the Vineland Adaptive Behaviour Scales II (VABS II) administered specifically for the study, in addition to the single routinely applied P scale score. Their data were used to determine the concurrent validity of the P scales and the VABS II and this was done using a cross-sectional descriptive design. For inclusion in this sample, the children had to have a P scale score, allocated within six months from the time of the assessment of adaptive behaviour. The rho co-efficient between the P scales and the Vinelands scale was anticipated to be .5. The sample size required to detect this with a p value of .05 and a power value of 90% was 37 (Statistica sample size calculation) [137]. In three centres (located in Winelands and Overberg) in which the P scales had been administered most recently, all children who had P scale scores allocated were considered participants. Due to lack of informed consent, one child was excluded, which left a sample of 41.

All children who had both P scale and gross motor function classification or both P scale and manual ability classification amounted to 181 participants. Children who had both P scale and communication function classification system scores amounted to 177. They formed the samples used to determine known group validity.

4.2.1.2 Participants: feasibility and acceptability of the P scales

The participants were the therapists and teachers who were employed by the WCED as professionals on the provincial outreach team. During the first provincial meeting in 2017, all of the attendees were approached to complete the questionnaire. Two team members indicated that they had not used the P scales. They were excluded from the sample.

4.2.2 Instrumentation and measurements

4.2.2.1 Function classification systems (appendix B1-3)

The classification systems were included to give a gross measurement of the level of activity according to the ICF Framework [127]. Classified into five levels, level one represents the least amount of physical disability and level five the most [46].

The Gross Motor Classification System was used to determine the level of mobility [45], the Manual Ability Classification System was applied to establish the level of fine motor control [46] and the

[9] Cohen classified effect sizes as small (d=0.2), medium (d=0.5), and large (d=0.8).

Communication Function Classification System (CFCS) indicates the communication ability of the child [47]. Also, see 2.5.

4.2.2.2 P scales

As described in 3.1.2.3, the most useful 'subject areas' were identified and implemented by the rural team. These were English, Mathematics and Physical Education. The subsections of English chosen were Speaking and Listening, while Using and Applying Mathematics was the subsection of Mathematics. This was done in order to enable the use of this outcome measure within the logistical constraints of service delivery in the current context. No adaptations were made to the instrument. However, for the purpose of giving an overview of the P scales, extracts from the level descriptors were used in Appendices C1-3

The data were re-coded into an ordinal 1-11 scale, where P1(i) was given a value of 1 and P8 a value of 11.

4.2.2.3 Vineland Adaptive Behaviour Scales II

This outcome measure was not included in the database, but was utilised to establish concurrent validity of the P scales. As a measure of change in adaptive functioning, the Vineland Adapted Behaviour Scale [48] includes the majority of measurable indicators of change in SPID. The following sections were used:

- Communication – Expressive; Receptive
- Daily living skills – Personal
- Socialisation – Interpersonal relationships; Play and leisure
- Motor skills – Gross motor; Fine motor

Vineland Scores indicated the age equivalent (years and months) and these were recoded into years, using decimals. Where an age equivalent of younger than one month (<0.08) was allocated, it was recoded into 0.07.

- English Speaking were compared to scores for Communication - Expressive
- English Listening were compared to scores for Communication – Receptive
- Both English Speaking and English Listening were compared to scores for Socialisation – Interpersonal relationships
- Using and Applying Mathematics were compared to scores for Motor skills (Fine motor) and Socialisation (Play and Leisure)
- Physical Education were compared to scores for Motor skills (Gross motor) and Socialisation (Play and Leisure)

4.2.2.4 Determination of 'known groups'

The MACS defined the known groups for Using and Applying Mathematics as this scale includes items such as handling items, feeling items and grasping. The GMFCS was used to form the groups for comparison with the Physical Education scale and the CFCS to compare the scores of both English Speaking and English Listening.

4.2.2.5 Questionnaire to establish acceptability and feasibility of the P scales (Appendix E)

A questionnaire (Likert scale) was developed and piloted on one of the rural team members (who was not a participant in this part of the study). The two questions related to the interpretation of the usefulness of the P scales and what level of experience the participant had in allocating P scale scores. The questions were well understood and were, thereafter, circulated to provincial SPID team members who have used the P scales. They were asked to complete this anonymously. These results were then analysed to establish acceptability and feasibility of the P scales in the current context.

4.2.3 Procedure

4.2.3.1 Training of the team in the use of the P scales

The therapists (occupational therapist, speech and language therapist and physiotherapist) that administered the P scales took part in one training session on the history and the P scale guidelines [11, 44, 125, 148]. Online tutorials developed in the UK were watched by the rural team and lessons learned during the piloting phase of validating the educational database were shared with the provincial team in 2014. They received no formal training in terms of the procedure for allocating scores, however. The four teams in the province discussed different methods of doing collaborative assessments during a second training session [44]. Best practices from this discussion were incorporated into the procedure followed by the rural team. This resulted in the speech and language therapist scoring English Speaking and Listening, the occupational therapist scoring Using and Applying Mathematics and the physiotherapist scoring Physical Education. Initially the psychologist assessed the subject area of Personal and Social Health Education (PSHE) and Citizenship. All five team members (including the educator and psychologist) then discussed the scores of all four subject areas. Scores of the three chosen subject areas were compared to the subject area of Personal and Social Health Education (PSHE) and Citizenship and collaboratively agreement was reached on scores of 122 children who formed part of the sample used to validate the educational database [44]. This process of moderation within the rural team enabled a certain amount of uniformity in applying the P scales. Issues related to the scoring were an ongoing discussion, both in the rural team and during another focused discussion of the provincial team in 2016.

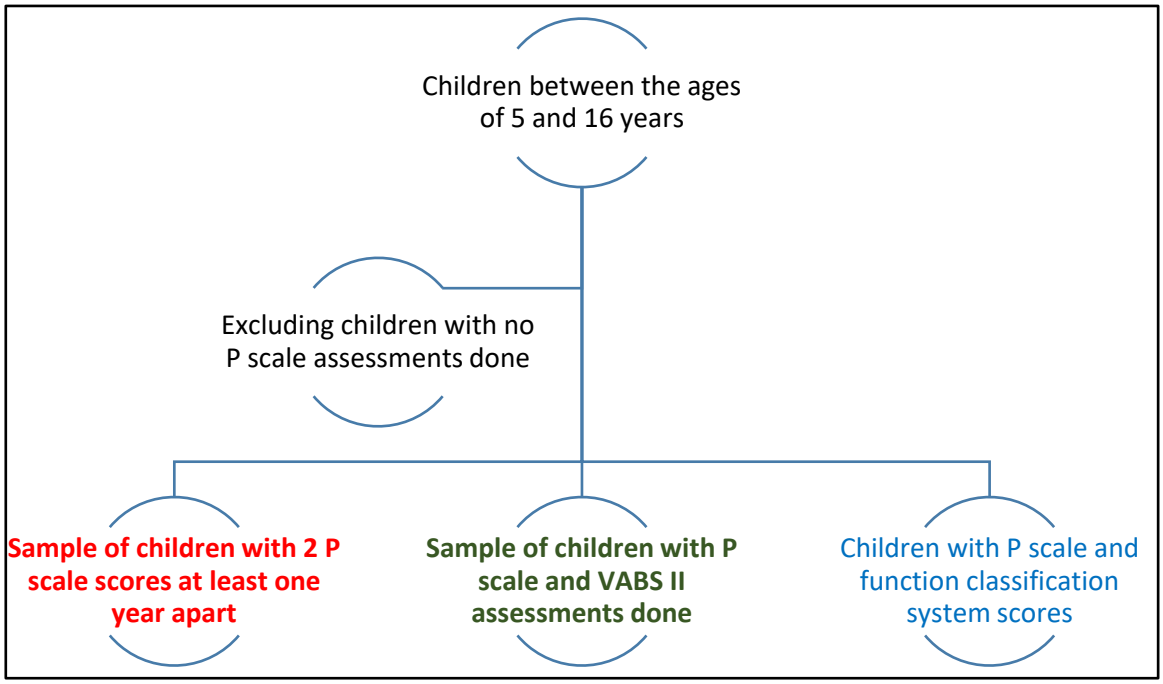
4.2.3.2 Permission to conduct study

The process followed is described in 3.1.3.1. The registration numbers with UCT HREC are (HREC REF: 109/2016) for the database and (HREC REF; 634/2016) in order to conduct this study. This process included obtaining permission from WCED Directorate: Research, parental consent and information

letters to the special care centres, WCFID and Association for persons with a disability (APD) (Appendix D).

4.2.3.3 Recruitment

The process of recruitment can be seen in the following flow chart (Figure 8).



Red = reliability and responsiveness sample
Green = concurrent validity sample
Blue = known group validity

FIGURE 8: FLOW CHART OF RECRUITMENT

Reliability, internal consistency, responsiveness and convergent validity: The routine database, excluding any children whose parents had not granted blanket permission to use their children's information for the purpose of research, were used. All 83 children who had two P scale scores allocated at least one year apart were selected from the database.

Concurrent validity: As the administration of the VABS was additional to the routine assessments included in the blanket consent signed by the guardian, the principle investigator approached the guardians of possible participants via the centre manager of three SCCs in which the P Scales had been administered most recently. All children who had P scale scores allocated were considered as participants. Due to lack of informed consent, one child was excluded.

Informed assent was gained from the children and/or their direct care worker on the day of the VABS II assessments (Appendix H). The VABS II assessments were done via a caregiver interview with no physical handling of the child. Team members were well aware that the study population is a vulnerable group due to age and diagnosis. Every possible precaution was taken to avoid the infliction of harm or putting them at risk during routine P scale assessments. Ethical considerations of autonomy, informed consent, confidentiality, beneficence and non-maleficence were respected at all times.

Known group validity: All children who had both P scale and gross motor function classification (181), manual ability classification (181) or communication function classification system (177) scores, constituted the samples used to determine known group validity.

Acceptability and feasibility: The provincial SPID team members who attended the first provincial team meeting anonymously indicated, according to their experience, the helpfulness of the use of the P scales in this field, using a five point rating scale. Twelve out of the twenty provincial team members determined the usefulness as well as usage of the P scales.

4.2.3.4 Assessment and data collection

Reliability, responsiveness and internal consistency: A standard procedure was followed in the allocation of P scale scores, both for the first, historical score and for the second score. Following an initial screening assessment, the child was observed at least three times over a period of not less than one month, during a variety of activities. Case discussions took place and after at least two of three therapists on the team reached consensus about the P scale scores indicated for each child, it was marked off on a printed list of the level descriptors. These were then filed as part of the individual support plan in the individual file of the child, which is kept at the SCC. Scores were also recorded in the individual files kept by the outreach team. Review scores were allocated in the same manner after at least one year.

Known group validity: The P scale scores were obtained as mentioned above. The classification system score allocation (GMFCS, MACS and CFCS) was performed during, or shortly after, the initial screening assessment and indicated on the ISP of the child.

Concurrent validity: The VABS II was used to examine concurrent validity of the P scales. The standard procedure was followed in the allocation of P scale scores by three therapists. The rural team psychologist, who did not participate in the P scale assessments of the three subject areas under investigation, performed the VABS II assessments - on a different day and without knowledge of the P scale scores indicated for those children.

4.2.3.5 Data handling and record keeping

Reliability, internal consistency, responsivity and convergent validity

The researcher collected data from individual files in the rural SPID team's centre folders. The test scores were entered and the information added to the children's information already logged into the routine database. Back-up and record keeping procedures were followed as outlined in 3.1.3.

Concurrent validity

The psychologist from the rural outreach team supplied the student with an Excel spreadsheet with the results from the VABS II assessments. These were entered into the database. Where a score of <0.08 was allocated, it was substituted with 0.07 to enable statistical analysis.

4.2.3.5.1 Acceptability and feasibility

The completed questionnaires were collected and filed along with the back-up copies of the database.

4.2.4 Data analysis

Reliability (internal consistency) was determined by the Cronbach's alpha. Comparing two independent samples with the non-parametric sign tests, the effect size was calculated in order to establish responsiveness over the period. The Mann-Whitney U test was used to compare P scale scores on two known groups in order to establish known group validity. P scale scores for English Speaking were compared for groups with or without the ability to communicate effectively according to CFCS. Physical Education scores were evaluated for groups with or without independent mobility (GMFCS). P scale scores for Using and Applying Mathematics were measured against the known groups of children with or without the ability to manipulate objects successfully (MACS). The MACS were chosen, because actions words like 'grasping', 'co-active exploration', 'hold a favourite object', 'handling and feeling the texture of objects' and 'manipulating objects' are used in the level descriptors of Using and Applying Mathematics (Appendix C3). These actions pertain to the ability of a person to use his/her hands.

Concurrent validity was determined through use of the Kruskal-Wallis test (ANOVA). Spearman's correlations with the Vineland Adaptive Behaviour Scales were used to establish concurrent validity. For children where a score of less than 0.08 (age equivalent of less than one month) was indicated, it was substituted with a value of 0.07 for the purposes of analysis. English Speaking (P scales) were compared to age equivalent of communication – expressive (VABS). Similarly were English Listening, Using and Applying Mathematics and Physical Education compared to communication – receptive, fine motor and gross motor respectively.

A panel of experts who have used the P scales established its acceptability and feasibility. Using five point Likert scales, the usefulness as well as usage of the P scales were determined by members of the provincial outreach team.

4.2.5 Ethical considerations

Detailed written explanations on the study objectives, aims, methodology, benefits and strategies were supplied via the centre manager (Appendix G). The centre manager was assisted to interpret the content for the relevant guardian and an interpreter utilised to translate where language barriers existed. Reasonable time was allowed to the guardian to consider the study invitation and guardians of the participants had the autonomy (at any time and without the fear that it would hinder their access to services in the future) to decide to withdraw from the study. Interviews were not requested of any parents before signing informed consent forms and it was accepted that they were sufficiently informed of the aims of the study.

No names of the child, guardian, care worker, manager, governing bodies, NGOs or specific SCCs were included in the thesis or will be in any articles that might be published in the future. Participant information, consent forms, pictures and videos are stored in secure, lockable cupboards in offices at the special school where the team is based. It is accessible to only the rural team members.

The study population is a vulnerable group due to age and diagnosis. Every possible precaution was taken to avoid the infliction of harm or putting them at risk of non-maleficence). To ensure justice, all participants received support according to the strategy employed by the rural team. Support was rendered after the child's enrolment at the centre, thus enrolment was not affected. When parent interviews took place, parents received training on how to include their child in everyday activities, working towards a common goal as set out in the individual support plan of the child.

Participants are likely to benefit from the results of this study. Team members will discuss the current nature, content and frequency of support by the team and positive results will be integrated into their model of support. Negative results/factors will be investigated and support altered where feasible and in the best interest of the child. This information will be shared with other teams working in the metropolitan area for their consideration. Results will also be communicated to the WCED directorate of inclusive education, involved in strategic planning in terms of service delivery to the whole of the Province.

Risks to the student were no different to the risks involved in day-to-day routines. Benefits outweighed the minimal risks. The team psychologist was available for counselling, had there been the need. Ethical considerations of autonomy, informed consent, confidentiality, beneficence and non-maleficence were thus respected at all times.

4.3 Results

4.3.1 Demographic details of the participants

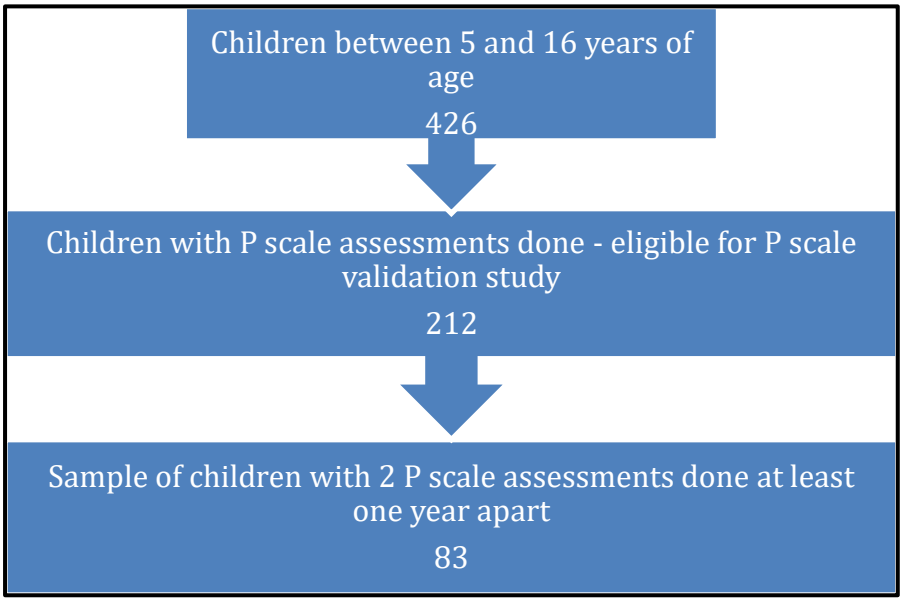


FIGURE 9: FLOW CHART OF ASSESSMENTS TO DETERMINE RELIABILITY AND INTERNAL CONSISTENCY

Two hundred and twelve children were assessed using P scales. One hundred and twenty-eight children were assessed once and 84 children had two assessments. One child had two assessments done less than a year apart and was excluded. The final sample included 83. The time between assessments ranged between 1.2 and 2.6 years with a median of 1.8 years (Figure 9).

The mean age of the sample on assessment was 11.1 (SD=2.6 range 6.9 – 16.8) and this was not significantly different to the children who had a single P scale score (t with separate variances =1.3, p=.185) (note that only children aged 5-16 years were eligible for a P scale assessment). Males constituted 62.7% of the retested sample and gender was independent of sub-sample or larger sample (Chi-sq =.402, p=.526). Further demographic details are described in Appendix J and Chapter 5 (section 5.2.1) as these characteristics were more pertinent to the aim of that chapter.

4.3.2 Validation of the P scales

The internal consistency was very high (Cronbach's alpha .99) and all four items correlated highly with one another (average inter-item correlation=.96) (Table 17).

TABLE 17: INTERNAL CONSISTENCY FOR ALL P SCALE SCORES

	English Speaking	English Listening	Using and Applying Mathematics	Physical Education
English-speaking	1.000	0.988	0.946	0.949
English Listening	0.988	1.000	0.964	0.954
Using and Applying Mathematics	0.946	0.964	1.000	0.955
Physical Education	0.949	0.954	0.955	1.000

n=83. P<.001 in every instance

The internal consistency was determined for P scores from P3(ii) upwards; it was still high (Cronbach's alpha .99) but lower compared to results for all the P scale scores (average inter-item correlation =.71) (Table 18).

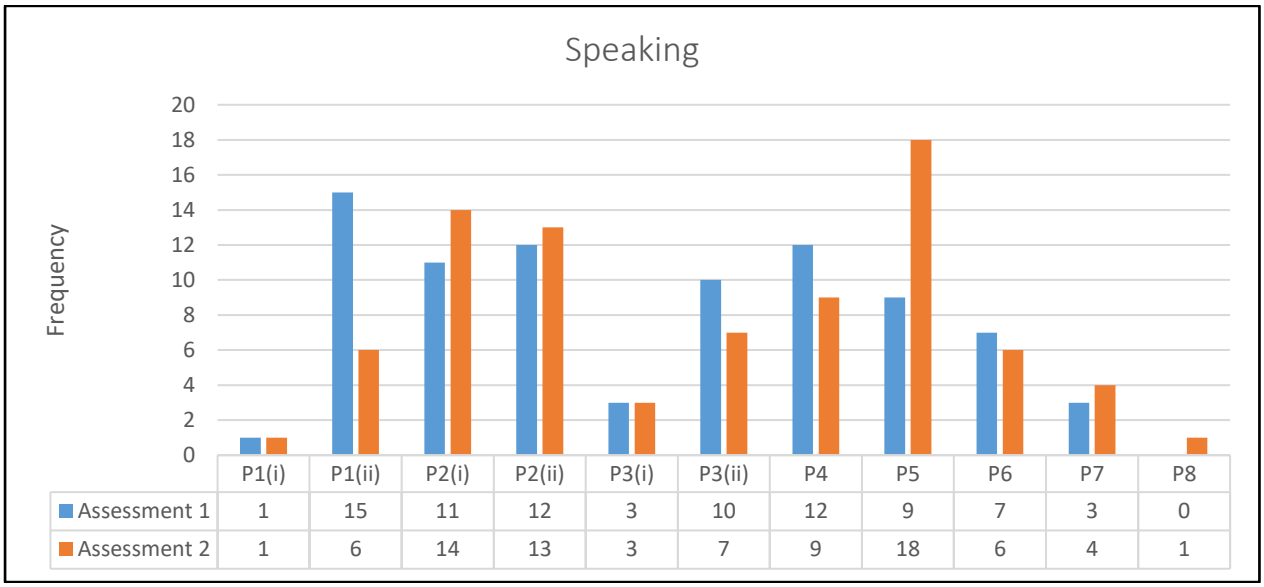
TABLE 18: INTERNAL CONSISTENCY FOR P SCALE SCORES ABOVE P3(I)

	English Speaking	English Listening	Using and Applying Mathematics	Physical Education
English Speaking	1.000	0.885	0.667	0.604
English Listening	0.885	1.000	0.818	0.634
Using and Applying Mathematics	0.667	0.818	1.000	0.674
Physical Education	0.604	0.634	0.674	1.000

Excluding those with score less than 6 (P scale score = P3ii). n=39 (case wise deletion of missing items). P<.001 in every instance

There was no difference in the mean ranking of the four P Scale scores - between those who had only one assessment and those that formed the sub-sample with two assessments (Speaking, z=1.18, p=.238; Listening z=.98, p=.326; Mathematics z=.0.94, p=.347; and Physical Education z=1.29, p=.199).

The distribution of P scale scores for English Speaking is depicted in Figure 10. A movement towards the right is seen in the frequencies of P scale score from the first to the second assessment.



*n=82 *One missing on second assessment*

FIGURE 10: DISTRIBUTION OF P SCALES FOR ENGLISH – SPEAKING

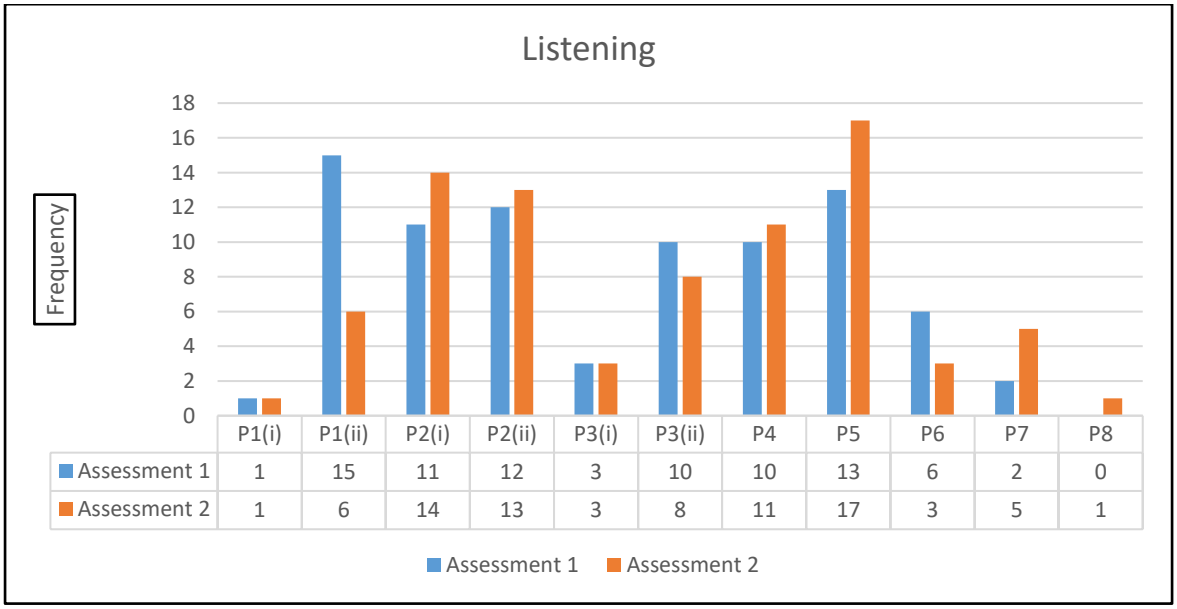
When the first and second assessment scores for English Speaking were plotted against one another, the scores of seven children were below the first assessment on the second assessment, 34 the same and 42 improved (Table 19).

TABLE 19: CHANGE IN P SCALE SCORES FOR ENGLISH - SPEAKING

Speaking	Second assessment	1	2	3	4	5	6	7	8	9	10	11	Row
First Assessment													
1		1											1
2			4	7	3								14
3			1	7	3								11
4					6	2	2	1	1				12
5						1	2						3
6							2	3	4				10
7					1		1	3	7				12
8								2	4	3			9
9									2	3	2		7
10											2	1	3
11												0	0
All Groups		1	6	14	13	3	7	9	18	6	4	1	82

*n=82 *one missing on second assessment*

The distribution of P scale scores for English Listening is shown in Figure 11. A movement towards the right is seen in the frequencies of P scale score from the first to the second assessment.



*n=82 *one missing on second assessment*

FIGURE 11: DISTRIBUTION FOR P SCALE SCORES FOR ENGLISH - LISTENING

When the first and second assessment scores for English Listening were plotted against one another, the scores of eight children were below the first assessment on the second assessment, 35 the same and 39 improved (Table 20).

TABLE 20: CHANGE IN P SCALE SCORES FOR ENGLISH - LISTENING

Listening	Second assessment	1	2	3	4	5	6	7	8	9	10	11	Row
First Assessment													
1		1											1
2			5	7	3								15
3			1	7	3								11
4					6	2	2	1	1				12
5						1	2						3
6							3	4	3				10
7					1		1	3	4				9
8								2	7	2	2		13
9									3	1	2		6
10											1	1	2
11													0
All groups		1	6	14	13	3	8	11	17	3	5	1	82

*n=82 *one missing on second assessment*

The distribution of P scale scores for Using and Applying Mathematics is shown in Figure 12. A movement towards the right is seen in the frequencies of P scale scores from the first to the second assessment.

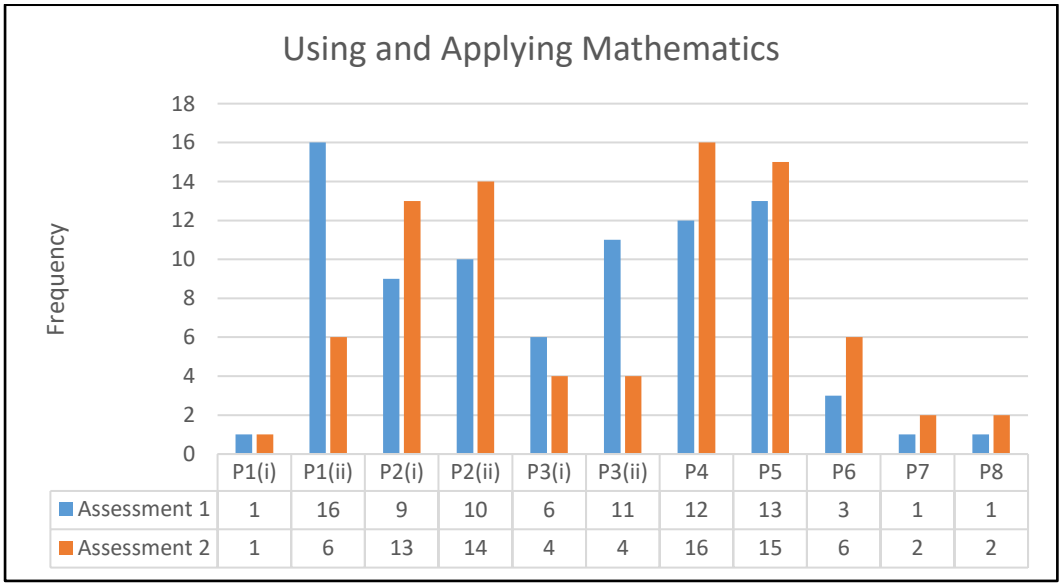


FIGURE 12: DISTRIBUTION OF P SCALE SCORES FOR USING AND APPLYING MATHEMATICS

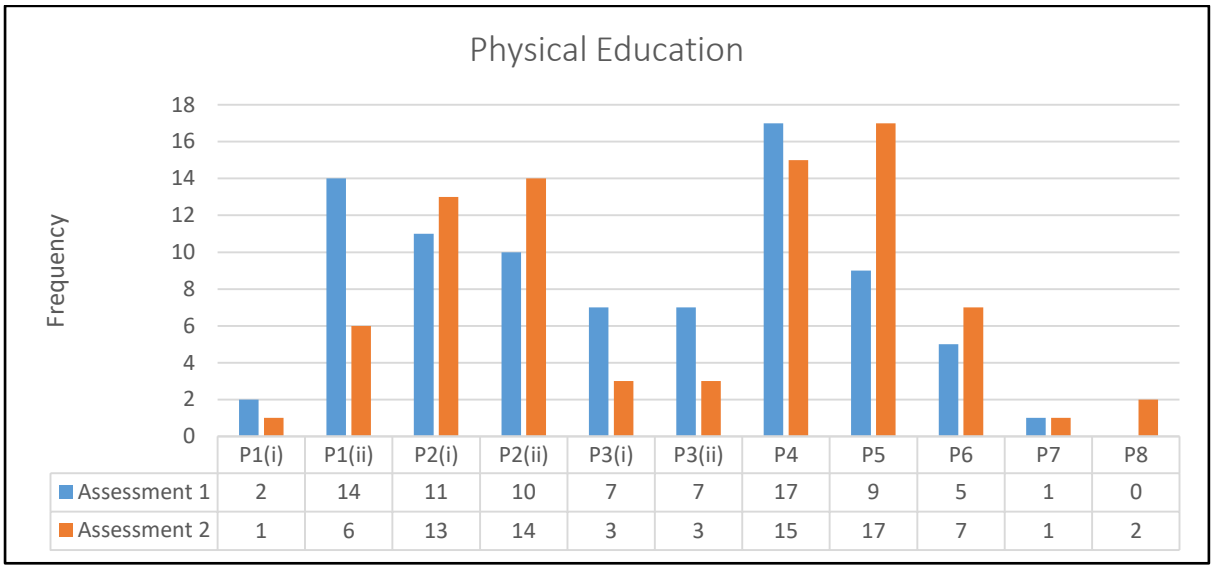
When the first and second assessment scores for Using and Applying Mathematics were plotted against one another, the scores of eight children were below the first assessment on the second assessment and 33 were the same and 46 improved (Table 21).

TABLE 21: CHANGE IN P SCALE SCORES FOR USING AND APPLYING MATHEMATICS

Using and Applying Mathematics	Second assessment	1	2	3	4	5	6	7	8	9	10	11	Row
First Assessment													
1		1											1
2			5	8	3								16
3			1	5	3								9
4					7	1	1	1					10
5						2	0	2	2				6
6						1	2	6	1	1			11
7							1	4	6	1			12
8					1			2	5	4	1		13
9								1	1	0	0	1	3
10											1		1
11												1	1
All Groups		1	6	13	14	4	4	16	15	6	2	2	83

*n=82 *One missing on second assessment*

In Figure 13, movement towards the right is seen in the frequencies of P scale scores for Physical Education, from the first to the second assessment.



*n=82 *One missing on second assessment*

FIGURE 13: DISTRIBUTION OF P SCALE SCORES FOR PHYSICAL EDUCATION

When the first and second assessment scores for Physical Education were plotted against one another (Table 22), the scores of six children were below the first assessment on the second assessment, 32 the same and 44 improved.

TABLE 22: CHANGE IN P SCALE SCORES FOR PHYSICAL EDUCATION

Physical Education	Second assessment	1	2	3	4	5	6	7	8	9	10	11	Row
First Assessment													
1		1		1									2
2			5	6	3								14
3			1	6	4								11
4					6	1	1	1					9
5						2	0	3	2				7
6							0	4	3				7
7					1		2	6	7	1			17
8									4	4	1		9
9								1	1	2	0	1	5
10											0	1	1
												0	
All Groups		1	6	13	14	3	3	15	17	7	1	2	82

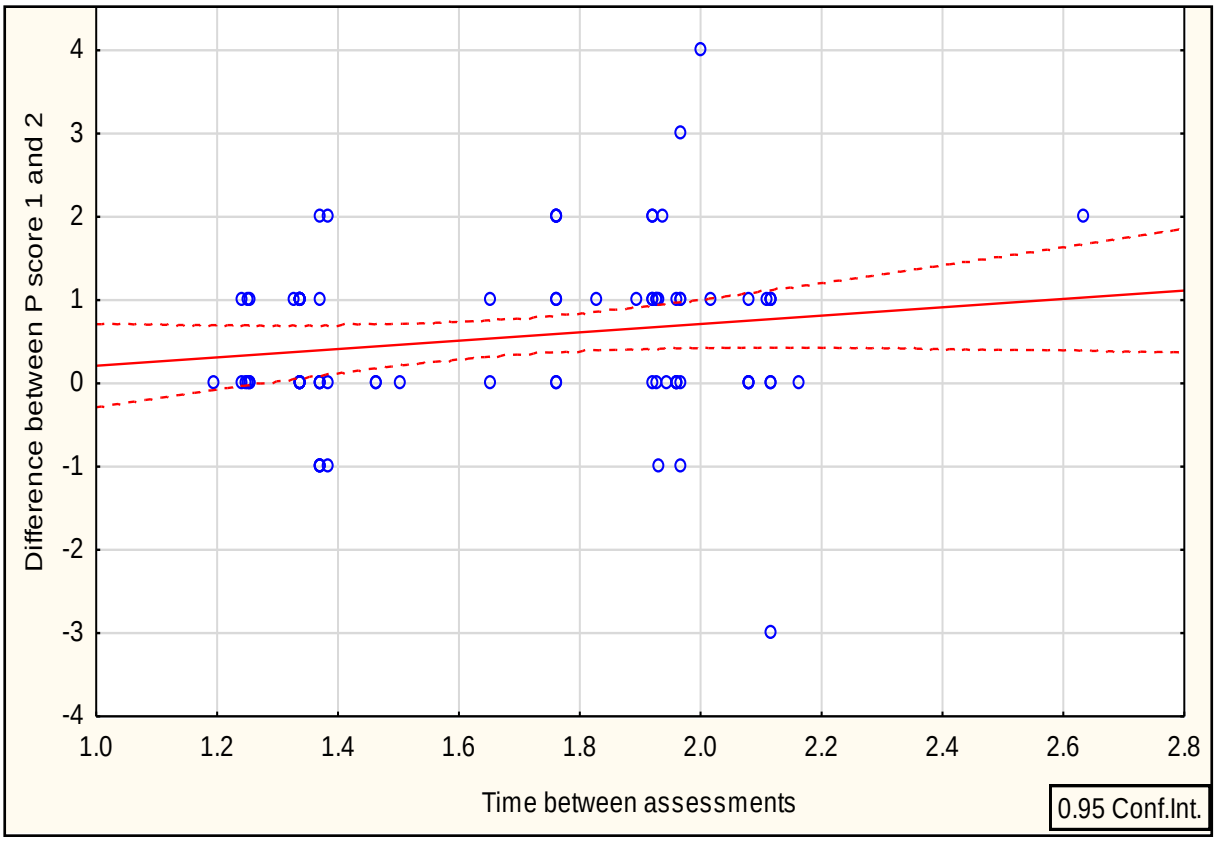
*n=82 *one missing on second assessment*

On comparison of the first and second scores, using the non-parametric Sign test, the ranking of the second score was significantly higher in every scale ($p<.001$) (Table 23).

TABLE 23: IMPROVEMENT IN P SCALE SCORES

	No. of non-ties	Percent of 2nd>1st	Z	p-value
English Speaking	48	85.42	4.763	***p<.001***
English Listening	47	82.98	4.376	***p<.001***
Using and Applying Maths	50	84.00	4.667	***p<.001***
Physical Education	50	88.00	5.232	***p<.001***

The time between assessments was not correlated with change in P scales (r = .17) (P=.127) for English Speaking (Figure 14).



*n=82 *case wise deletion of missing data*

FIGURE 14: SCATTERPLOT OF P SCALE (ENGLISH SPEAKING): ASSESSMENT 1 AND ASSESSMENT 2 AND TIME BETWEEN ASSESSMENTS

4.3.3 Known group validity

Of the 212 children who were assessed using P scales, 177 had the CFCS administered, 181 of these children also had MACS and GMFCS scores indicated on the database.

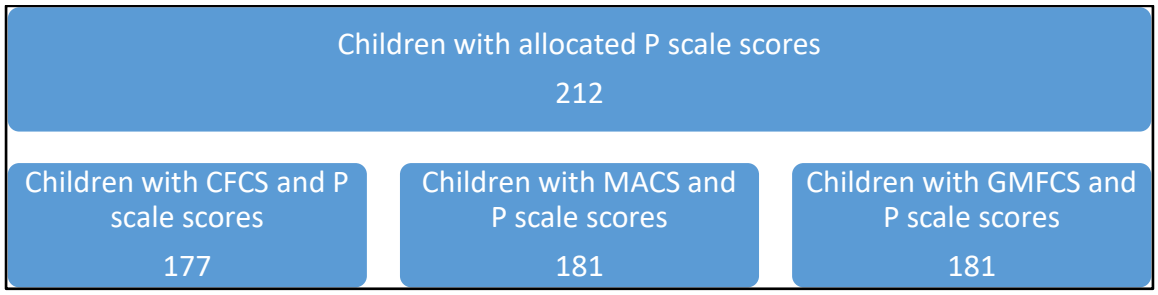


FIGURE 15: OUTLINE OF STUDY SAMPLE USE TO DETERMINE KNOWN GROUP VALIDITY

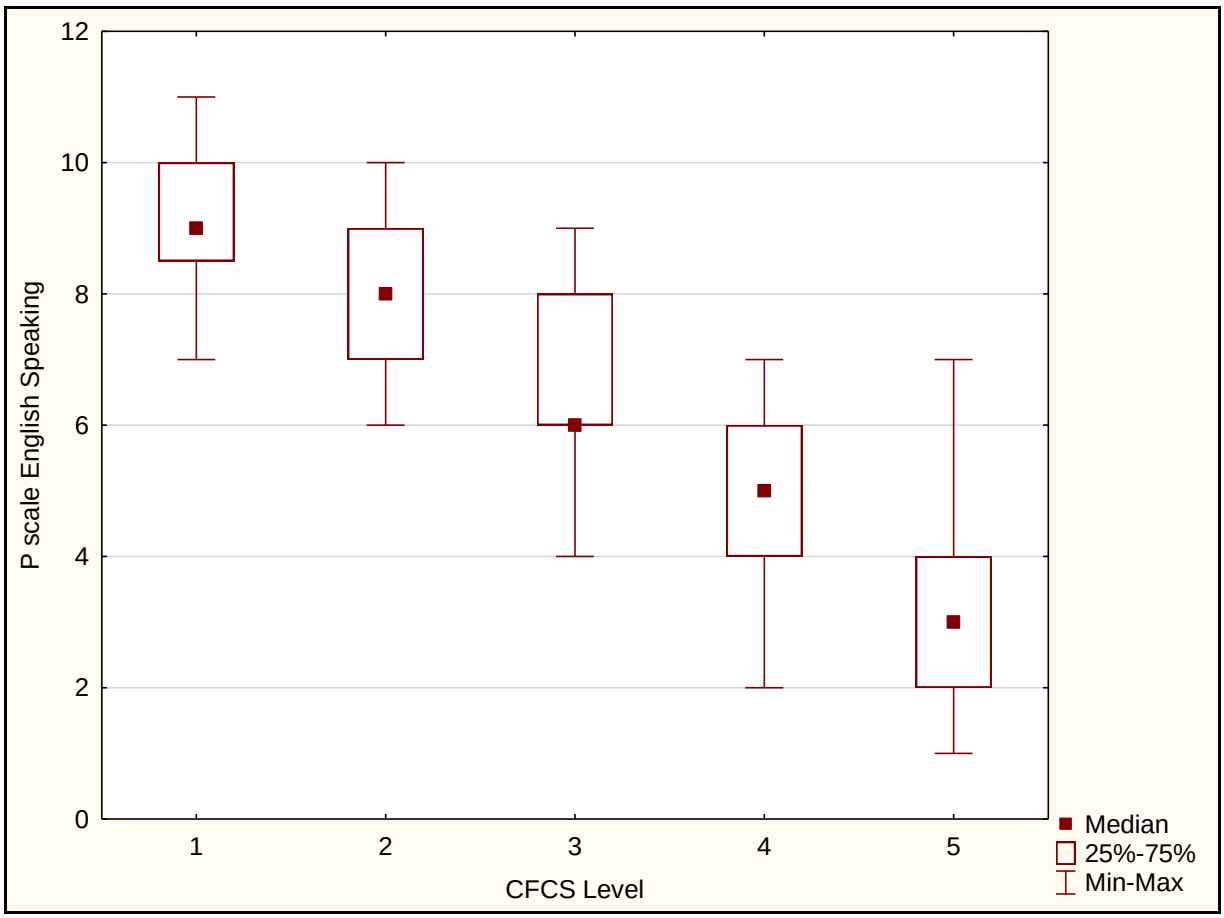
As can be seen in Table 24 below, the number of scores (English Speaking) that fall below the median increased as the ability to communicate deteriorated. Using the Kruskal-Wallis test, Chi-Squared were 135.81 ($p<.001$).

TABLE 24: MEDIAN P SCALE SCORES (ENGLISH - SPEAKING) VS CFCS LEVEL

	CFCS Level I	CFCS Level II	CFCS Level III	CFCS Level IV	CFCS Level V	Total
<= Median: observed	0	0	3	14	78	95
expected	19	9	9	13	43	
obs.-exp.	-19	-9	-6	1	35	
> Median: observed	36	18	15	11	2	82
expected	17	8	8	11	37	
obs.-exp.	19	10	7	0	-35	
Total: observed	36	18	18	25	80	177

n=177

As can be seen in Table 24, the number of children scoring less than the median score increased from 0 out of 36 in level I to 78 out of 80 children in Level V. The significant difference in the median scores reflected the decreasing performance from CFCS level from levels I - V.



n=177, Chi-Square = 65. df = 4 p <.001

FIGURE 16: P SCALE SCORES FOR ENGLISH - SPEAKING VS CFCS LEVEL

A similar pattern for the P scale Using and Applying Mathematics was observed when the scores were categorised by MACS Chi-Squared were 65.30 (p<.001) (Table 25) but the number in Level I who scored less or equal to the median was 15 out of 71 whereas the number in Level V was 38 out of 38.

TABLE 25: MEDIAN P SCALE SCORES (USING AND APPLYING MATHEMATICS) VS MACS LEVEL

	MACS Level I	MACS Level II	MACS Level III	MACS Level IV	MACS Level V	Total
<= Median: observed	15	20	6	13	38	92
expected	36	21	6	9	19	
obs.-exp.	-21	-1	0	4	18	
> Median: observed	56	22	6	5	0	89
expected	35	21	6	9	18	
obs.-exp.	21	1	0	-4	-18	
Total: observed	71	42	12	18	38	181

**n=181*

Due to the small number of children on MACS Level III, they were recoded as Level IV, and the following were seen:

TABLE 26: MEDIAN TEST – P SCALE SCORES (USING AND APPLYING MATHEMATICS) WITH MACS RECODED

	MACS Level I	MACS Level II	MACS Level IV	MACS Level V	Total
<= Median: observed	15	20	19	38	92
Expected	36	21	15	19	
obs.-exp.	-21	-1	4	19	
> Median: observed	56	22	11	0	89
Expected	35	21	15	19	
obs.-exp.	21	1	-4	-19	
Total: observed	71	42	30	38	181

**n=181*

As can be seen in Table 26, 15 of 71 children in level I scored below or equal to the median compared to 38 of 38 of children performing at a Level V. The decrease in performance in Using and Applying Mathematics, as the ability to manipulate objects decreases, is depicted by the almost linear decrease in median scores across levels in Figure 17. Using the Kruskal-Wallis test, Chi-Squared were 63.87 ($p<.001$).

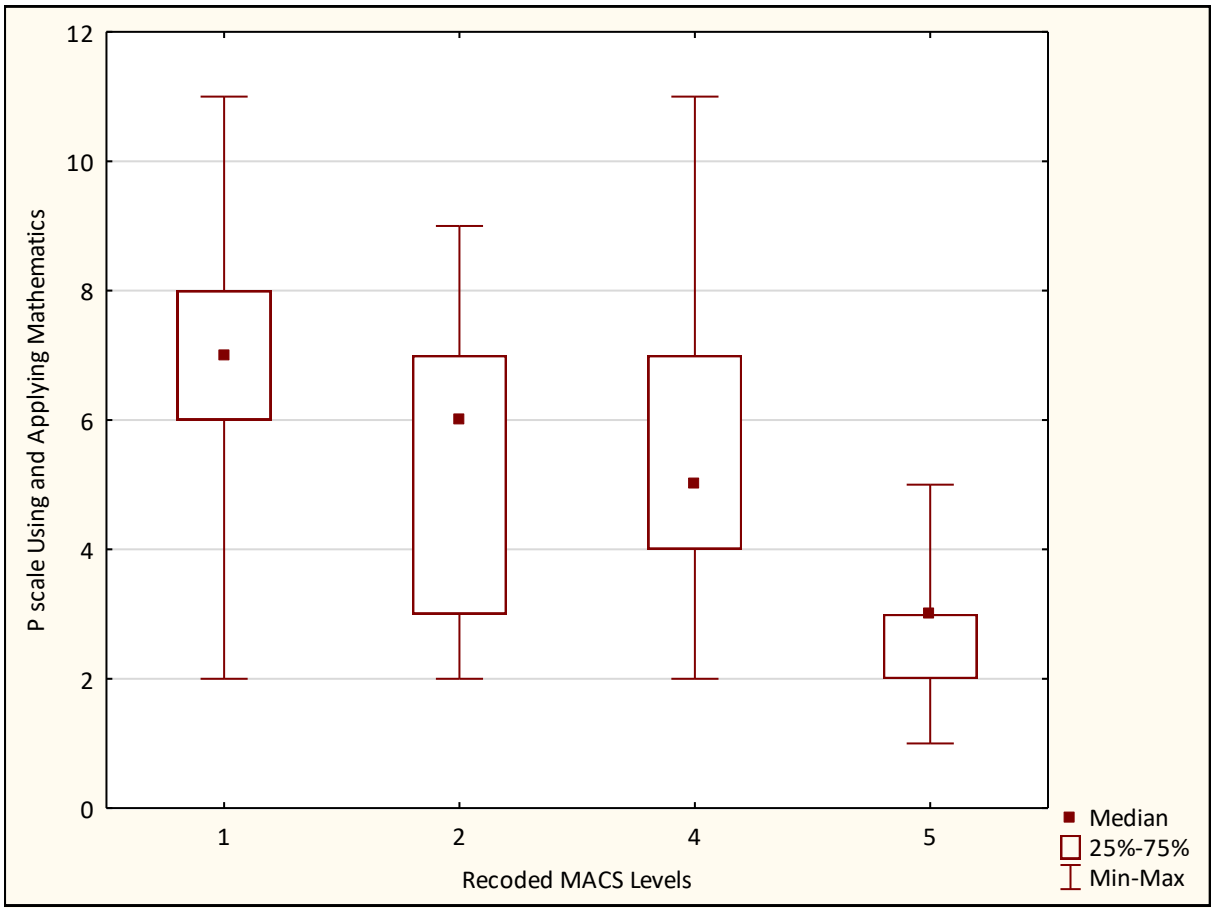


FIGURE 17: P SCALE SCORES FOR USING AND APPLYING MATHEMATICS VS MACS LEVEL (RECODED)

TABLE 27: P SCALE PHYSICAL EDUCATION VS GMFCS LEVEL

	GMFCS Level I	GMFCS Level II	GMFCS Level III	GMFCS Level IV	GMFCS Level V	Total
<= Median: observed	40	13	2	20	52	127
Expected	57	15	5	20	31	
obs.-exp.	-17	-2	-3	0	21	
> Median: observed	64	14	7	16	4	105
Expected	47	12	4	16	25	
obs.-exp.	17	2	3	0	-21	
Total: observed	104	27	9	36	56	232

As can be seen in the table above, 40 of 104 children in level I scored below or equal to the median and 52 of 56 in level V. There were nine children in level III and their median scores were higher than those in levels I and II. The medians were associated with the classification system scores, despite this anomaly (Kruskal-Wallis test, Chi-Squared = 48.29 p<.001).

Even when levels III - IV were collapsed, a pattern of decreasing performance was not evident (Figure 18).

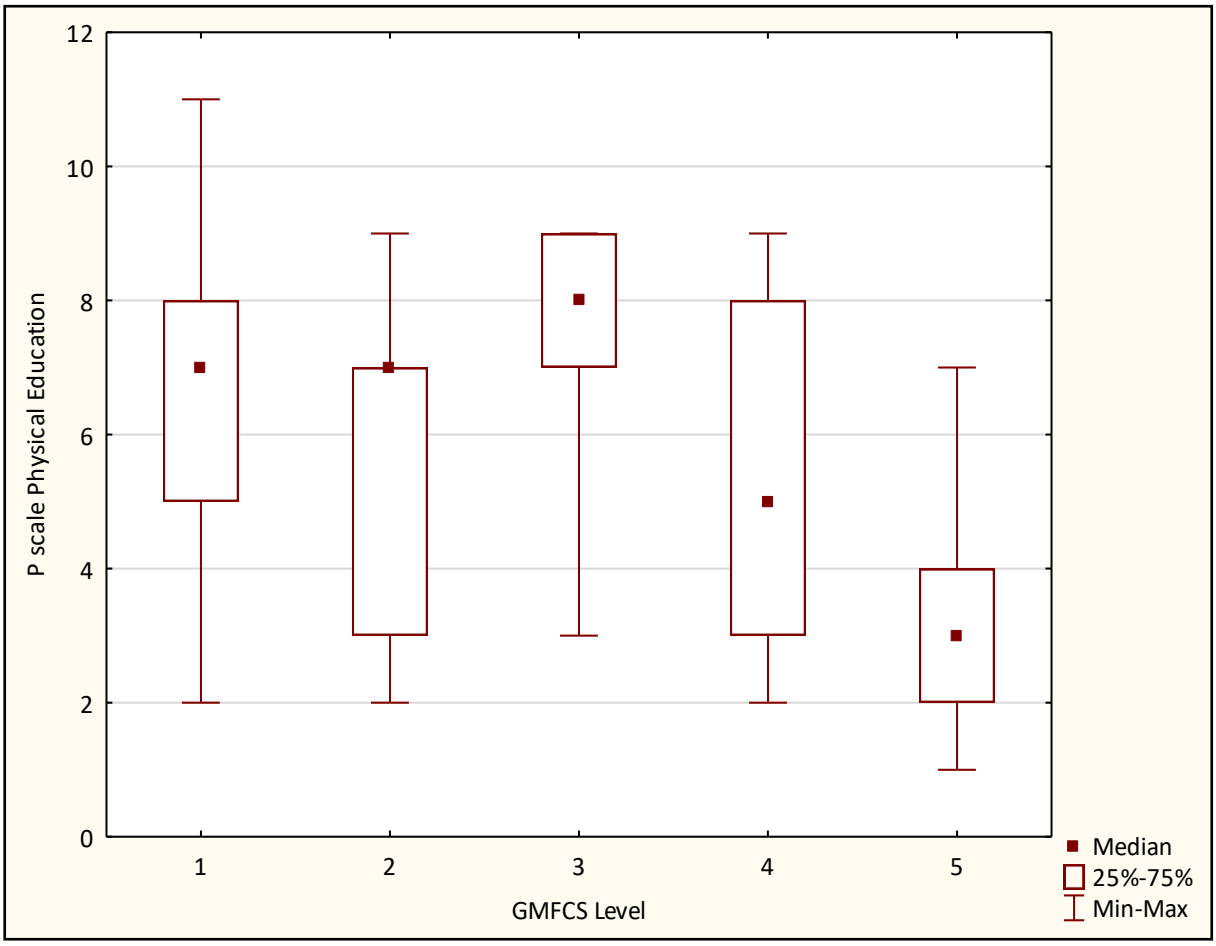


FIGURE 18: P SCALE SCORES FOR PHYSICAL EDUCATION VS GMFCS

Therefore, performance in P scale Physical Education was also compared to the MACS level. Of the children in level I, 15 of 72 scored equal to or below the median and 38 of 38 children in level V scored below the median (Table 28). Kruskal Wallis Chi-Square was 67.24 ($p<.001$).

TABLE 28: P SCALE PHYSICAL EDUCATION VS MACS LEVEL

Physical Education	MACS Level I	MACS Level II	MACS Level III	MACS Level IV	MACS Level V	Total
<= Median: observed	15	20	6	14	38	93
expected	37	22	6	9	20	
obs.-exp.	-22	-1	0	5	18	
> Median: observed	56	22	6	4	0	88
expected	35	20	6	9	19	
obs.-exp.	21	2	0	-5	-19	
Total: observed	72	42	12	18	38	181

n=181

The median score of the Physical Education scale decreased consistently from MACS level I through to level V (Figure 19).

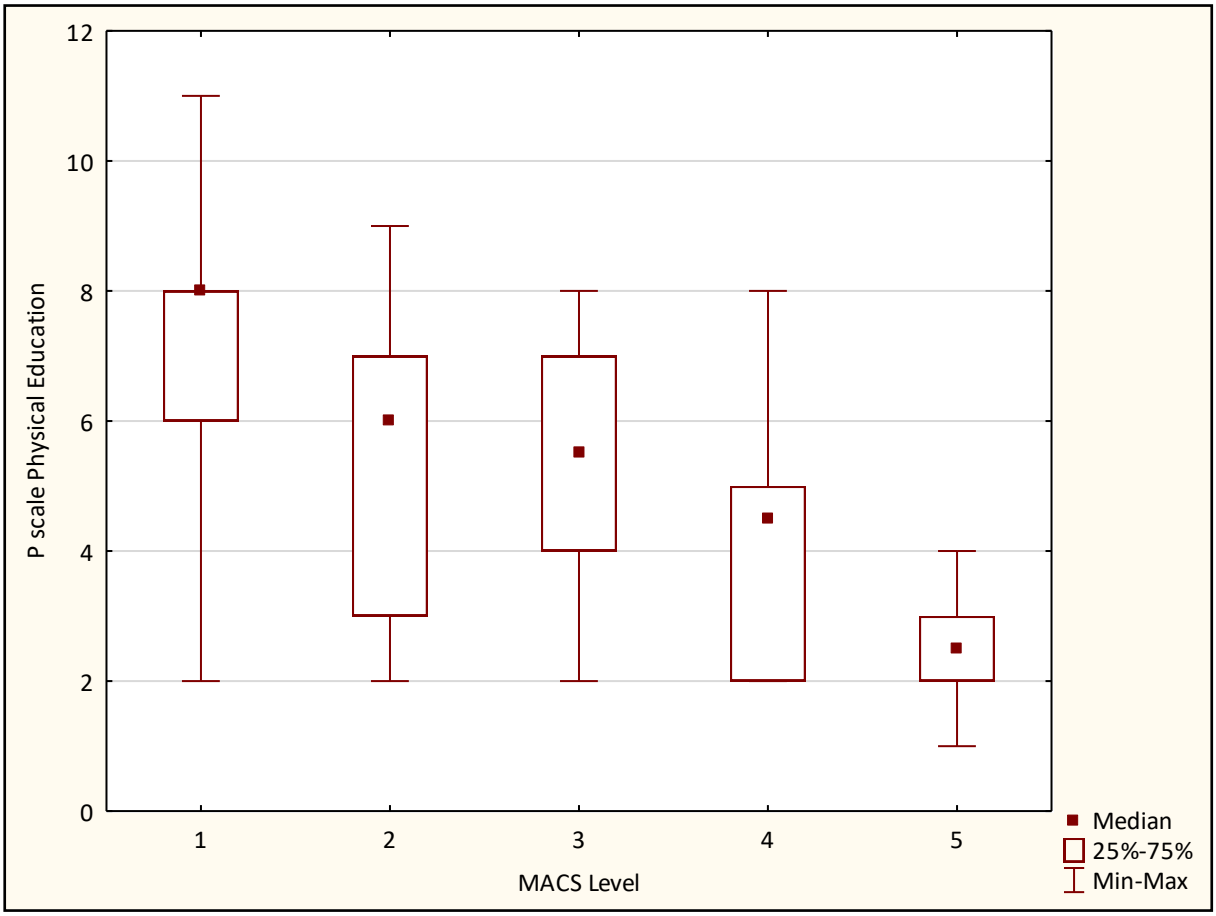


FIGURE 19: P SCALE SCORES FOR PHYSICAL EDUCATION VS MACS LEVEL

4.3.4 Concurrent validity with the VABS II

Of the 212 children who were assessed using P scales, 128 had been assessed once, of which 41 also had the VABS II administered (Figure 20).

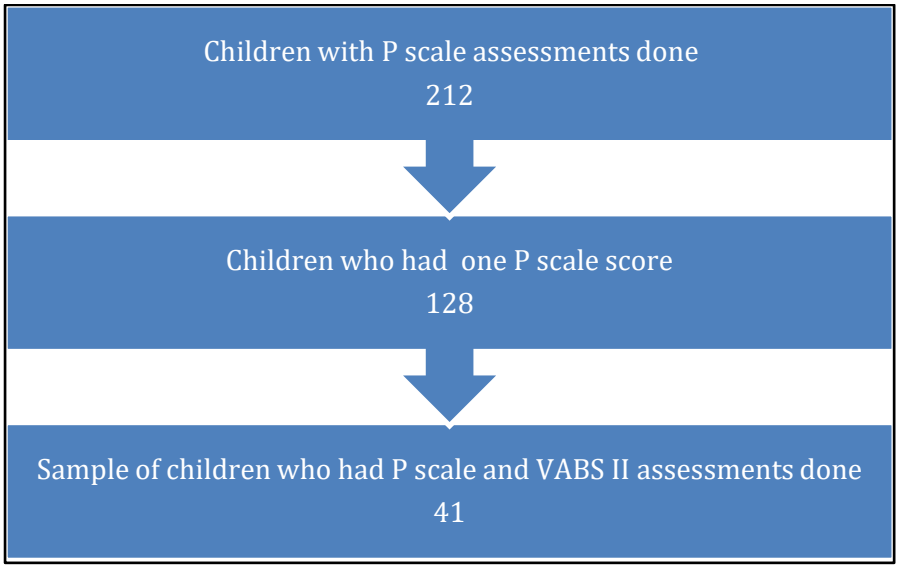


FIGURE 20: FLOW CHART OF ASSESSMENTS DONE TO DETERMINE CONCURRENT VALIDITY

There was no significant difference in age (t separate variances= .329, p=.887), gender (Chi-sq=1.5, p=.471) or severity as measured by the P scale English Speaking score (Z adj=-1.46, p=.145) of the sample used to establish concurrent validity.

The mean age equivalents for the VABS items were as follows:

Communication–expressive:	1.37 years (n = 41; SD = 1.12).
Communication–receptive:	1.90 years (n = 41; SD = 1.93)
Interpersonal relationships:	2.48 years (n = 41; SD = 1.88).
Fine motor ability:	1.87 years (n = 41; SD = 1.57)
Play and leisure:	2.12 years (n = 41; SD =2.2
Gross motor:	2.00 years (n = 41; SD = 1.6

The children had the lowest age equivalent score in Communication-expressive items and the highest in Interpersonal relationships.

The Spearman Rank Order Correlations for English Listening with Communication–receptive as well as with Interpersonal relationships can be seen in Table 29.

TABLE 29: SPEARMAN RANK ORDER CORRELATIONS FOR THE P SCALE AND VABS II ITEMS

P scales	VABS II	Spearman Rank Order Correlations	P value
English Speaking	Communication expressive	0.796	<.001
English Speaking	Interpersonal relationships	0.827	<.001
English Listening	Communication receptive	0.754	<.001
English Listening	Interpersonal relationships	0.806	<.001
Using and Applying Mathematics	Fine motor	0.659	<.001
Using and Applying Mathematics	Play and leisure	0.807	<.001
Physical Education	Gross motor	0.609	<.001
Physical Education	Play and leisure	0.836	<.001

*n=41

All paired items were highly correlated with the highest between Physical Education and Play and Leisure (rho=0.836 and the lowest between Physical Education and gross motor (rho=0.609).

4.3.5 Accessibility and feasibility

Twelve of the 15 provincial team members present at a provincial team meeting used Likert scales to rate how useful they found the P scales as an assessment tool. Two professionals indicated that they had not used the P scales and were therefore not willing to indicate usefulness.

TABLE 30: RATING OF USEFULNESS AND FREQUENCY OF USE

Frequency of use	<10	11-50	51-100	101-200	>200	Total
Very useful		4		1	1	6
Useful	1		1			2
Neutral	1	1				2
Hardly useful			1			1
Not useful		1				1
Total	2	6	2	1	1	12

n=12

Eight of the 12 reported that it was useful or very useful and ten had used it more than 11 times.

4.4 Discussion

The enrolment targets were met and, as the characteristics of the sample were similar to the entire group as reported in Chapter 3, the results are likely to be generalizable to all children supported by

the rural WCED team. However, the findings may not be applicable to other teams in the WC who have not had the same experience with the scales.

The P scales performed well and demonstrated a wide range of abilities in the children in each of the items. The internal consistency (reliability) (Cronbach's alpha) was very high in the whole sample (.99) but somewhat lower in the children who performed better (.71). The scale was responsive and the Sign test indicated improvement in every subject across time, with at least 39 of 82 children improving from the first to the second assessment. Known group validity was demonstrated and in every case the P scale subject score was significantly associated with the level of the corresponding classification system that was used. The P scale scores decreased in an almost linear pattern from level I to V (with small deviations in level III in two items). Concurrent validity, using the VABS as the gold standard, was demonstrated as each item was significantly correlated with the relevant VABS item (range rho=.61-.84). Eight of the twelve therapists reported the scale to be useful or very useful and seven of these had used the scale more than 11 times.

4.4.1 Validity of the P scales in the current context

Content and face validity have been established in the United Kingdom [51] and experts from the Department of Basic Education accepted it as such during the development of the Draft Learning Programme for learners with SPID (as a resource).

Due to the collaborative nature of scoring the P scales, internal consistency was chosen as a way to test the reliability of this outcome measure. Very high correlations were found between all subject areas, yet less so in the children who scored P3(ii) and above. It is likely that, in the more severely affected children, the different subjects all reflect a low global educational level and thus the high internal consistency in these children may be expected. In contrast, in the higher performing children, the correlation between the subjects, while still significant and high, was smaller. The two English subjects were highly correlated (rho=.89) and might tap into the same ability, but the other two subjects were less correlated which indicates greater differentiation in performance in subject areas. The high correlation between the subject areas in the children performing at a lower level might indicate that the use of all subject performance tests is redundant as the information gained by one subject is replicated in the other subjects. It may therefore be adequate to use a single scale to monitor performance in children performing below a P3(ii) level. On the other hand, the discrimination between curricular areas above P3(ii) allows for greater targeting of different subjects.

The literature review indicated that there was a lack of responsive outcome measures in SPID [20, 96] and a perception that children with SPID are unlikely to improve their learning performance over time [11]. Therefore, responsiveness is an important factor to consider for this group. The P scales were responsive in detecting changes across all subject areas. Since so very little improvement is expected in a child with profound intellectual disabilities, any change is of clinical importance. This part of the study showed that about half of the study population showed improved performance implying that learning had occurred. This demonstrates that children can improve and that the P scales have the ability to monitor clinically important that progress in this population over time. The

P scales were found to detect changes irrespective of the time between assessments, with a tendency towards increased attainment as the time between assessments increases.

Known group validity was demonstrated and the scores of children on different levels of the classification systems showed a consistent decrease in P scale scores (performance decreased) as the classification level increased (ability decreased). This assumption was substantiated by Smits et al (2011), who determined that in children with CP, "low levels of non-verbal intellectual capacity" are found in more severe forms of CP [149]. The scores decreased in an almost linear pattern from level I to V, with small deviations in level III of GMFCS and MACS. One of the exceptions was the performance of GMFCS level III children who showed better than expected performance in Physical Education than those in level I and level II. There were only a few children in level III for both GMFCS and MACS, possibly due to a previous lack of early intervention – which could have resulted in contractures and deformities, which, in turn, could have prevented the child from, say, learning to walk with an assistive device. This means a GMFCS score of IV could have been allocated to a child who would have scored as GMFCS III, had he not developed the deformities. Since the availability of walking devices was not reported, it is also possible that unavailability of walking devices could have influenced the scores in a similar manner. Then a possibility of bias also existed. Score allocations were done in a pragmatic situation by persons who knew the child. The P scales also allow for accommodations according to different disabilities. For instance, activities for Physical Education may be executed by use of arm movements, in the absence of lower limb function. For these reasons, MACS levels were used instead, to show that convergence existed between Physical Education and the ability to manipulate objects successfully.

Concurrent validity was demonstrated with the gold standard measure, the VABS II, in four domains of performance, namely motor skills, daily living skills, communicative skills and social behavioural skills. Intuitively, it would be expected that the results will be related and, indeed, it showed significant, high correlations. Significant correlations were found between the P scale English (Speaking and Listening) and both VABS items communication (expressive and receptive) and social behavioural skills (interpersonal relationships). This finding highlights the importance of communication in establishing interpersonal relationships, but it may also reflect a global inability to perform.

Using and Applying Mathematics showed better correlation with play and leisure than with fine motor scores on the VABS II. This might be a result of accommodations and adaptations made to activities used to assess performance in Using and Applying Mathematics. When a child has poor ability to grasp, exploration of objects by using other body parts may be observed - for instance, using arms, feet or mouth. Many of the P scale level descriptors can all be achieved without the use of hands (use of eye movements, remembering or anticipating "learned responses", paying attention, problem solving, decision-making, matching, sorting and copying a pattern). This might explain the weaker correlation with fine motor scores on the VABS II. In turn, these same abilities described in the P scale level descriptors, also form the basis for sensory-motor and constructive play. Another factor which could lead to the higher correlation with play and leisure was the fact that phrases in the P scale descriptors ("show interest", "seek attention", "participate in activities", "initiate interactions", "role-play" and "scoring in games") all represent the constructs of social play, also measured by VABS II.

The same tendency, for similar reasons, was found in Physical Education, where the P scale score in Physical Education was more of an indicator of the abilities measured by the VABS II - play and leisure, than that of gross motor capacity. The highest correlations were found between English (Speaking and Listening) and interpersonal relationships, followed by Physical Education with play and leisure.

The majority of the professionals considered the P scales to be a useful assessment tool and, from those, most agreed that it was very useful indeed. However, most professionals have used this assessment tool only on 50 or less children, indicating that there are factors hampering the routine use of the P scales amongst many professionals.

4.4.2 Strengths and limitations of validating the P scales in the current context

The P scales is a participation level assessment tool, measuring performance and not capacity, in a pragmatic environment not necessarily conducive to optimal results. This limited the possibility to do blinded measurements and could have let to bias. The P scales have been validated in this context, but it does not mean that a person with no knowledge of the child will get the same results. Information from parents and care workers is essential [150]. The study provides evidence that, within the context of the study, the P scales are valid and reliable. Thus, they are valid when members of the rural team of the WCED apply the scales - as they have received training (although limited), went through a process called moderation and assess the children collaboratively. It cannot, however, be concluded that the same degree of validity would be found if the scales were used by other WCED teams with less experience of the use of the scales and with a different method assigning performance levels. The results of this study cannot therefore be generalised to other contexts.

Yet, the findings show that there are implications for routine use, as regular contact between professional, child and caregivers is a necessity. In the event that contact (centre visits per professional) is limited, a collaborative approach amongst team members and good relationships with SCC care workers is needed. A collaborative approach implies that services are not compartmentalised into specific disciplines, but strategies, which are integrated into a functional context, are planned jointly in order to address the complex needs of children with SPID [107]. High staff turnover of both care staff and outreach team members were some of the challenges faced [36]. Amongst other factors, this could explain the less frequent use of the P scales by teams in the metropolitan areas, which probably influenced results on the acceptability and feasibility of using the scales routinely.

However, the research does provide proof of concept. The members of the rural team can use the P scales with a high degree of confidence and, if a similar methodology is followed, it is likely that other teams could utilise the scales effectively as well.

In order for the P scales to be used in future studies, it would be advisable for the researcher to determine reliability. Due to time and resource constraints, inter- and intra-rater reliability, test-retest reliability and measurement error were not examined and was a shortcoming of this study.

4.4.3 Conclusions and recommendations

When applied, using the described methodology by members of the rural team of the WCED, the P scales demonstrated validity, reliability and responsiveness. The scales would therefore appear to be a very useful measure of performance and their routine application at regular intervals is recommended. The optimal time between assessments needs to be established - based on the feasibility of annual or bi-annual assessments, and the rate of progression of individual children.

It is recommended that outreach teams limit initial P scale assessments to English Speaking and Physical Education, as these were found to be the most responsive subject areas and correlated well with measures of adaptive functioning. Limiting the number of subject areas could improve the possibility for it to be a feasible, routine outcome measure. During revision of scores, in the presence of childhood behavioural disorder, or when a child scores higher than P3(ii), it becomes necessary to assess more subject areas. This will allow for differentiation between subject areas and can guide practitioners to the specific skills needed for optimal performance.

The significant findings in terms of the validity of the P scales should be shared with other provincial team members. One of the limitations in this study, were limitations in training of those who administer the P scales. This is crucial to address. Guidelines should be set on accommodations and adaptations made in the allocation of scores. With continuous training and through a process of moderation, access to and ultimately acceptance of the P scale as a routine outcome measure can become a reality. In turn, having data on the performance outcomes of the wider population in the WC could prove to be very valuable in tracking individual as well as group performance. This could assist in monitoring the efficacy of program implementation, which would in turn lead to improved outcomes for these children.

This study lays the groundwork which, together with the validated database [44], enables future research to expand upon the pioneering work done by the teams in the WC. It is proposed that wider use of the P scales should be encouraged and documented as more teams are rolled out across the country. Keeping records and analysing repeated P scale scores over an extended period could give valuable insight into the learning curve of a child with SPID. In addition, the responsiveness of the instrument means that it provides valuable information relating to effective management strategies. In order to utilise these results, careful recordkeeping of interventions or support strategies are necessary. This possibility is explored and described in Chapter 5.

Chapter 5. Educational support offered by the WCED rural team

5.1 Background

The approach to educational support differs across and within WCED teams providing support to children with SPID. The aim of this chapter is, firstly, to document the nature and frequency of intervention provided by the rural team – both therapeutic and educational. The interdisciplinary nature of the intervention and the emphasis on education rather than on rehabilitation required the development of non-traditional approaches to support, particularly for the therapists who formed part of the team. It is important that the different prongs of the support intervention be recorded to provide the intervention context against which any change in the children's performance could be understood.

As it emerged from the previous chapter, the P scales were responsive to change and the scores could be utilised as a measure of improved performance. It was thus possible to begin an exploration of the factors that may relate to this improvement. A secondary aim of this chapter was to pilot the use of the P scales, as a participation-level measure of educational performance, in identifying which factors were associated with an increased chance of improved performance. The factors, identified through use of the ICF conceptual framework, included personal factors, health conditions, functional performance and, most importantly, the nature of educational intervention.

The anticipated outcome was that younger children might show greater improvement, as the child's nervous system might still be developing. The expectation was also that those without associated medical conditions would improve more from the first to the second assessment, as these conditions could result in illness and time away from the SCCs. It was unclear if those with more or less severely affected functional abilities would demonstrate the greatest gains in performance on the P scales. With regard to the community and learning environment, the expectation was that those who received support in their home language (concordant language) would show more improvement. Finally, the impression of the researcher was that children who received multi-professional intervention - direct as well as indirectly via care worker training - responded better than those who had not been in receipt of such a comprehensive support package. However, it was the expectation that those who did receive an individual intervention had a better chance to show improved performance.

This analysis would be of use in exploring the feasibility of using the P scales as an outcome measure and identifying which independent variables might be associated with improvement. In future, it might be possible to use larger samples to compare the impact of different service delivery models.

5.2 Methodology

A descriptive analytical longitudinal record review was used to establish which factors, if any, were related to educational performance, over a period of at least one year. Repeated measures of the P scales for Physical Education, Mathematics and English (Speaking and Listening) were used to establish whether a child showed improvement in the ability to participate in educational activities

or not. The median of the P scale scores for the four areas (Speaking, Listening, Using and Applying Mathematics and Physical Education) were calculated for both the first and the second assessment. The difference between the medians thus determined how the variable of progress was dichotomised: improvement vs no improvement (including regression).

The information of the 83 children, which was utilised for the validation study described in Chapter 4, were used for this section of the research. The sample of convenience thus included all children, aged 5-16 years, who had two P scale scores allocated by the rural team for children with SPID between 2014 and 2017. Multiple logistic regression, as part of the retrospective study to examine factors related to change, requires a minimum of 10 subjects per variable [151]. The sample of 83 described in Chapter 4 allowed for the analysis of a maximum of eight variables.

5.2.1 Instrumentation and measurements

The validated database was utilised to determine the demographic information, medical characteristics and support needs of participants. The items included on the database have been described previously (4.1.2) (Appendix A) and are not listed here. Previous chapters did not document the details of service delivery and these are included below.

5.2.1.1 Description of the WCED rural team intervention programme and development of a questionnaire to describe this

A questionnaire was developed to gather information with regard to support services received by the participants between two assessments. It was based on the researcher's first-hand knowledge and participation in the development of the rural team support. The collaborative approach to program development makes it difficult to separate therapy from education and different therapy fields from one another. The focus therefore falls on support to access the curriculum (i.e. subject areas described in the draft Learning Program for children with SPID). The support required is normally multi-dimensional, involving mostly all professionals. All children in this study population had access to therapeutic services from WCED.

Strategies are set for interventions based on recommendations for individual support, yet educational support needs are mainly addressed through group activities and through care worker training. Children are mostly not withdrawn for therapy, but their support needs are addressed within the classroom or group environment. Therapeutic and stimulation activities are integrated into a daily program and the emphasis is on inclusion. The content of activities and training was not based on CAPS, but on the content of a draft framework[10]. In order to create a responsive environment where active learning takes place [152], care worker training is of a practical nature, where activities are modelled, monitored and repetitive assistance is given.

The content of the questionnaire, to extract data on educational support services received, is depicted as part of Appendix A – items 66-71. As these items did not form part of the validated

[10] Draft Framework for Therapeutic and Stimulation Programme: Children with severe to profound intellectual disability, developed by Provincial CSPID team November 2012, submitted to WCED

database [44], it was piloted on 22 children from one SCC. Content and face validity were established by consulting a panel of experts. Item 32 – Therapeutic services (non-WCED) was also split into two in order to differentiate between services from the Department of Health vs other therapists. Due to the findings of the pilot, the question about content of support was divided into two parts (group vs individual support) as was the question about the frequency of support (visits vs individual support) – see 5.2.1.1. The phrasing of the question on parental involvement was changed from "What form of parental contact took place?" to "Did the team meet with the parent or guardian to discuss individual support?"

The motivation for inclusion and the definitions of the items included in the questionnaire are listed and discussed below.

The team visited the SCCs at regular intervals, but due to various logistical constraints there was no consistency in the amount received. In order to reach more children and more centres, the team increasingly operated in a transversal fashion [33, 107]. This meant that not all team members would visit the same centre on the same day, but team members would rather split up in order to accommodate more than one SCC on a given day. Professionals would thus monitor and assist SCCs with activities developed by another team member. The minimum that any one profession would visit a specific SCC was set out to be once a term or twice over six months.

The f**requency of visits** was thus the total number of centre visits done by any team member. Some centre visits did not involve direct contact with children, but indirect support through workshops for staff, parent meetings or meeting with role-players. This was different to the f**requency of individual support.** This number reflects the number of days that a child received individual therapeutic support from one or more therapist on the team.

Based on the collection of individual support plan goals of each SCC (group support plans), integrated programs were developed to address these needs. This meant that one activity would address two or more of the following areas of development: communication, motor skills, social skills, life skills and perceptual/pre-perceptual skills. Initially, these programs (various integrated activities) took into account centre-specific needs and available resources. Gradually group programs became more generic and all SCCs would receive exactly the same programs. Parallel to the development of the Learning Program, these activities focussed on the three subject areas – not in isolation, but all subject areas were addressed in one slot of the daily program. Therapeutic principles were imbedded into the content and implementation strategies of these programs, which consisted of various structured activities. Structured activities are pre-planned activities presented in a specific way and with specific outcomes in mind.

The **nature of the support** that a child received from the team can be considered as either direct or indirect support. Direct support pertains to direct exposure to the facilitator (therapist or educator) in both group and child-specific therapeutic activities. Activities, designed according to individual support needs*,* were named an *individual program* and were accompanied by care worker training on child-specific needs. Alternately, direct support was rendered in order to optimize participation during structured activities, which was also considered individualized support.

A child could be supported in a group, where *structured group activities* were implemented by the team and executed by the care worker on a daily basis.

Individual and group support meant a child took part in group activities, but also had individualized support from a therapist. When other therapists were involved in individual intervention for a child at a specific SCC, the team would concentrate more on programs for the group, to prevent duplication of therapeutic services. It was therefore possible that more children did receive individual therapeutic input from the DoH or other therapists. The input from non-educational therapists was not included and only WCED interventions were analysed.

A child who was in a classroom where no structured activities were implemented by the team, but the SCC staff had received training via workshops or discussion groups, were regarded as having had *indirect support – caregiver training.*

A child who received support in all of the above was deemed to have received a *comprehensive support* package.

The **content of support,** rendered in group fashion, was of both an educational and therapeutic nature and developed by all professions represented in the team. Usually, a team member implemented these activities once. The care worker then repeated the activities in a group and the team monitored this during the subsequent centre visit. Care worker training was done to ensure optimal learning during the execution of the activities.

Group support could include the following:

Classroom structure and function reflected the input required to enable a responsive environment, where optimal learning can take place. This included making changes to the physical environment in the classroom and planning/changing the daily, weekly or monthly schedule of activities. A set routine was encouraged and the implications on behaviour explained. Although mainly the function of the educator, the entire team was involved to accommodate individual needs within the group. Grouping of children with similar functional abilities and taking into account the age were counted in this category.

Gross motor activities were those implemented in the specific slot of the daily program that aimed to develop motor skills (as part of the subject area of Life Skills). They included large bodily movements to improve mobility, balance and physical skills that included the use of various apparatus and sporting equipment.

Fine motor activities were mainly implemented as table activities in the specific slot of the daily program that aimed to develop manipulative skills. Although these activities also addressed perceptual and pre-perceptual skills, the primary aim of the activities was to enhance manual ability.

Basic perceptual activities were implemented to develop basic concepts such as colours and shapes. Activities to develop matching, sorting and sequencing skills formed part of this slot in the daily program.

Integrated self-care activities were those implemented with the aim of developing optimal independence in self-care. These would include stories, action songs, discussion groups and the physical execution of the task, for instance brushing teeth.

Sensory activities, including art, were those activities designed to encourage exploration using the different senses. These were performed as table, floor or outdoor activities.

Music and dance included activities that incorporated use of action songs and enjoying music. These would include the songs and rhymes of a morning or social ring.

Multi-sensory storytelling is a substitute for reading stories. The stories are developed to be short and about familiar actions and objects. Language is kept simple, hand signs are included and repetition is a prerequisite. Exploration of concrete objects or sounds formed part of the activities.

Teaching the specific use of sign language and/or visual schedules were considered to be *communication activities* – which should have been applied throughout the day.

Both *mobility and positioning activities* were those specifically designed for a group of children with physical disabilities - where adapted participation in the gross motor activities (for the mobile) alone were not sufficient to meet their physical needs. This included a schedule for performing individual (therapeutic) programs to enhance mobility and a schedule for positioning routines in the group.

Age appropriate activities of daily living (ADLs) were those activities implemented in order to develop optimal independence in daily living, including domestic and basic work skills for an adolescent group.

Age appropriate social activities were recreational activities designed specifically for the adolescent with SPID.

Social-emotional activities consisted of discussion groups where the sense of self and sexuality were addressed, mainly in the adolescent with SPID.

The content of ***individual support*** refers to child specific therapeutic input, in order to improve daily functioning and optimize participation in group activities. This could involve the following:

Communication – Addressing individual needs through therapeutic input and child-specific care worker training, for example, the use of Alternative and augmentative communication (AAC) on choice making or the interpretation of the subtle signs of an attempt to make needs known.

Behavioural support – Child-specific care worker training on handling the difficult situations arising from the behaviour of a child.

Integrated self-care – Child-specific care worker training on the inclusion of mobility, sensory stimulation and communication during the physical execution of a self-care action.

Integrated play – Individual therapeutic input and child-specific care worker training on the inclusion of play and communication during positioning of a child with a physical disability. It also pertains to play activities designed to address a combination of communication, motor and perceptual skills of the mobile child.

Fine motor, sensory and perceptual – individual therapeutic input and child specific care worker training in order to facilitate optimal development in these fields. It included grading and adaptations made to enable inclusion of the individual in fine motor, sensory and basic perceptual group activities.

Gross motor play – Child-specific care worker training on the facilitation of optimal participation of the child during gross motor group activities by making adaptations to the activities and/or apparatus.

Activities were developed and implemented by the WCED team, but ultimately implemented by the SCC staff. Since no recording of the frequency of execution by the SCC staff could be found, the team (represented by any one or more team members) is considered the interventionist.

5.2.2 Procedure

5.2.2.1 Permission to conduct study

The process followed was as described in 3.1.3.1. The registration numbers with UCT HREC are (HREC REF: 109/2016) for the database and (HREC REF; 634/2016) in order to conduct this study. This process included obtaining permission from WCED Directorate: Research. Parental consent was obtained as part of routine practice and information letters were issued to the special care centres, WCFID and Association for Persons with a Disability (APD) (Appendix D).

Routine data were used and no additional assessments done. Information on service delivery (nature, content and frequency of support) were extracted from Annual and Term Reports, Weekly Reflections and visit reports to the specific centre. This included information on parental contact made by the team and the SCC.

With the exception of accessing and recording data related to support services, the process of data collection, data handling and record keeping were the same as described in 3.1.3.

5.2.2.2 Data analysis

Descriptive statistics were employed for the characteristics of the children, parental involvement as well as the nature, content and frequency of the intervention.

At the outset of the study, it was intended to use multivariate logistic regression to identify the factors that increased the odds of improvement. However, as bivariate analysis did not identify any factors which were associated with outcomes and missing data reduced the number of participants, binary multiple logistic regression analysis [153] was not used to establish the relative odds of each factor with regards to improvement/no improvement. Instead, the t-test was used to establish if the ages of those who demonstrated and did not demonstrate improvement was the same and the nature and frequency of support, associated medical conditions, language concordance and functional abilities were categorised into meaningful binary categories. The odds ratios and 95% confidence intervals were then calculated.

5.3 Results

5.3.1 Demographics and information on additional therapeutic support

These are very similar to the characteristics of the entire sample of children receiving services from the rural team as described in Chapter 3 and presented in Appendix J. Information that is additional is given in this section.

Apart from WCED therapists, some children had input from the Western Cape Department of Health and/or other therapists. These additional therapeutic services are displayed in Table 31. Fifty-eight percent of children received input from therapists from the Department of Health, mainly the provision of assistive devices. Forty-seven percent of the participants received input from other therapists (mainly supervised under-graduate students). Combined analysis showed that 62 (74.7%) of the children in this sample had access to therapeutic services other than those of the outreach team.

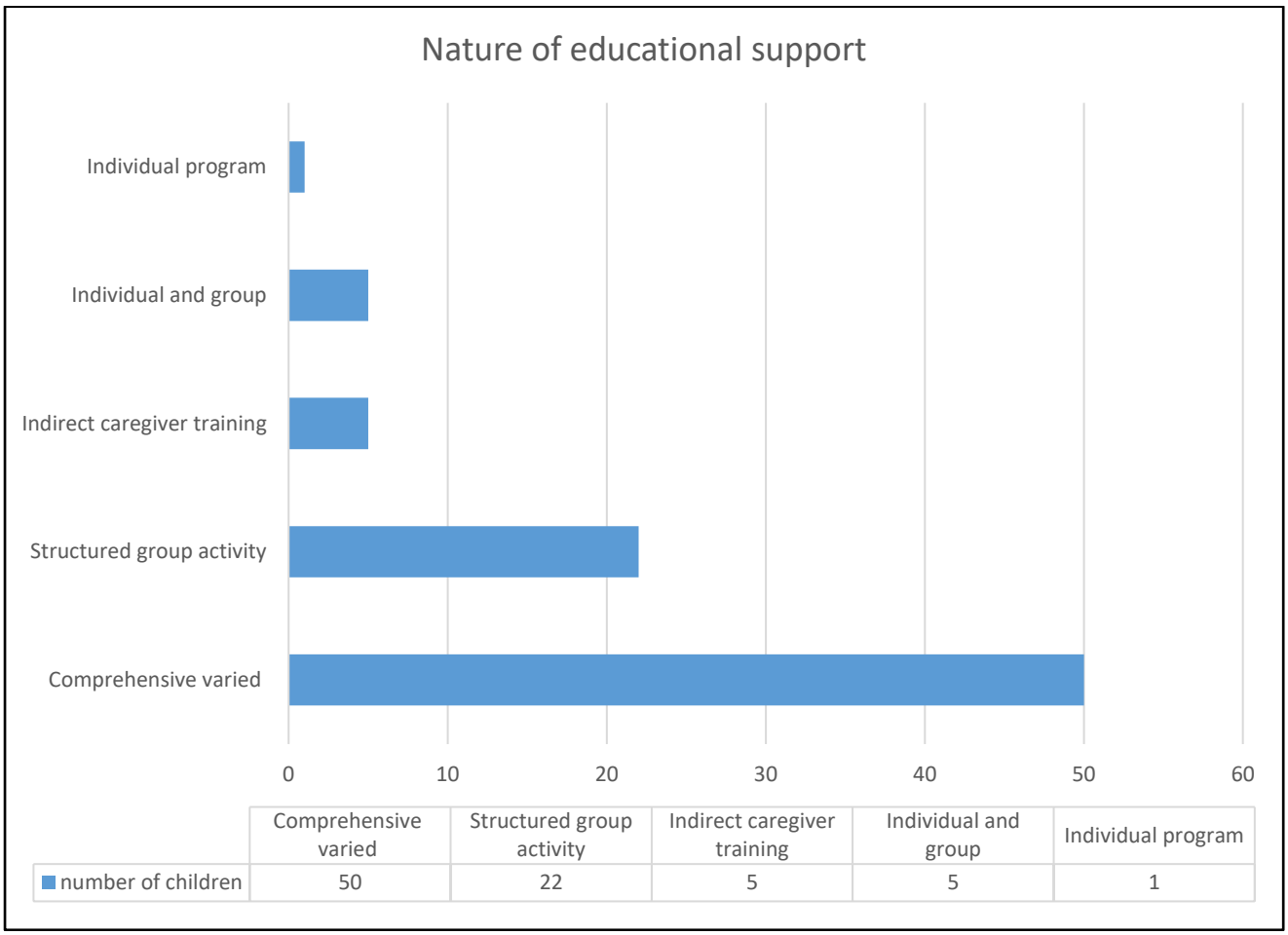
TABLE 31: THERAPEUTIC SERVICES PROVIDED BY OTHER ORGANISATIONS (IN ADDITION TO WCED)

		Count	Percent
Western Cape DoH	None	34	41.0
	Assistive devices only	20	24.1
	In centre: multi-disciplinary	16	19.3
	Outpatient: multi-disciplinary_	2	2.4
	In centre: physiotherapy	3	3.6
	Outpatient: physiotherapy	2	2.4
	Outpatient: speech therapy	3	3.6
	In centre: OT	2	2.4
	Unknown	1	1.2
	Total	83	100
Students	Students: multi-disciplinary	15	18.1
	Student speech therapy	15	18.1
	Volunteer physiotherapy	5	6.0
	Student physiotherapy	3	3.6
	NGO funded therapeutic services	1	1.2
	None from students/NGOs	44	53.0
	Total	83	100
Summary access	Access to additional therapeutic services	62	74.7
	No access to additional therapeutic services	21	25.3
	Total	83	100

5.3.2 Intervention – educational and therapeutic support from WCED

The nature of support from the inter-professional team from WCED, as defined in 5.2.1.1, is depicted in Figure 21. Fifty (60.2%) received a combination of all the support forms - both direct and indirect support. Twenty-two (26.5%) received educational and therapeutic support as part of the group (without receiving individual therapeutic input from WCED therapists). Five received individualized therapeutic support, in addition to structured group activities – whereas only one child received individual therapeutic support from WCED in isolation. Only five children were not in receipt of any

form of direct support, but were indirectly supported by the fact that care worker training was done on general issues and principles pertaining to education of the child with SPID.

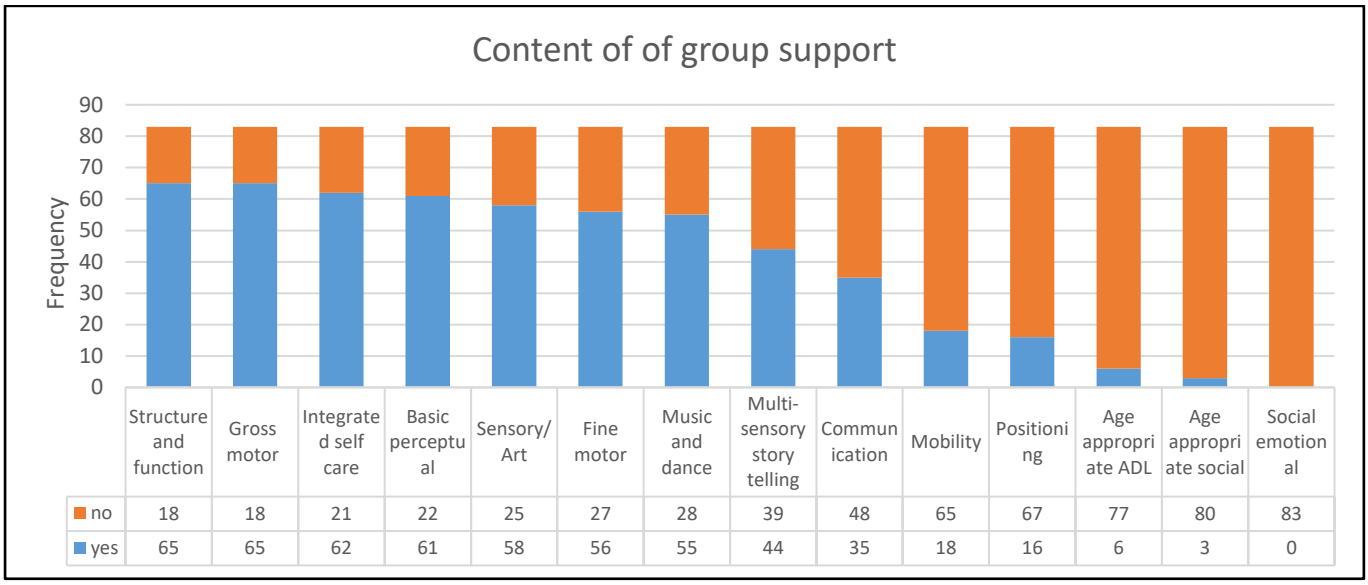


n = 83

FIGURE 21: NATURE OF SUPPORT FROM INTERPROFESSIONAL OUTREACH TEAM

In terms of the frequency of support, 49.4% of children attended a SCC that was visited more than 12 times. The number of visits, between assessments, ranged between five and 26 days.

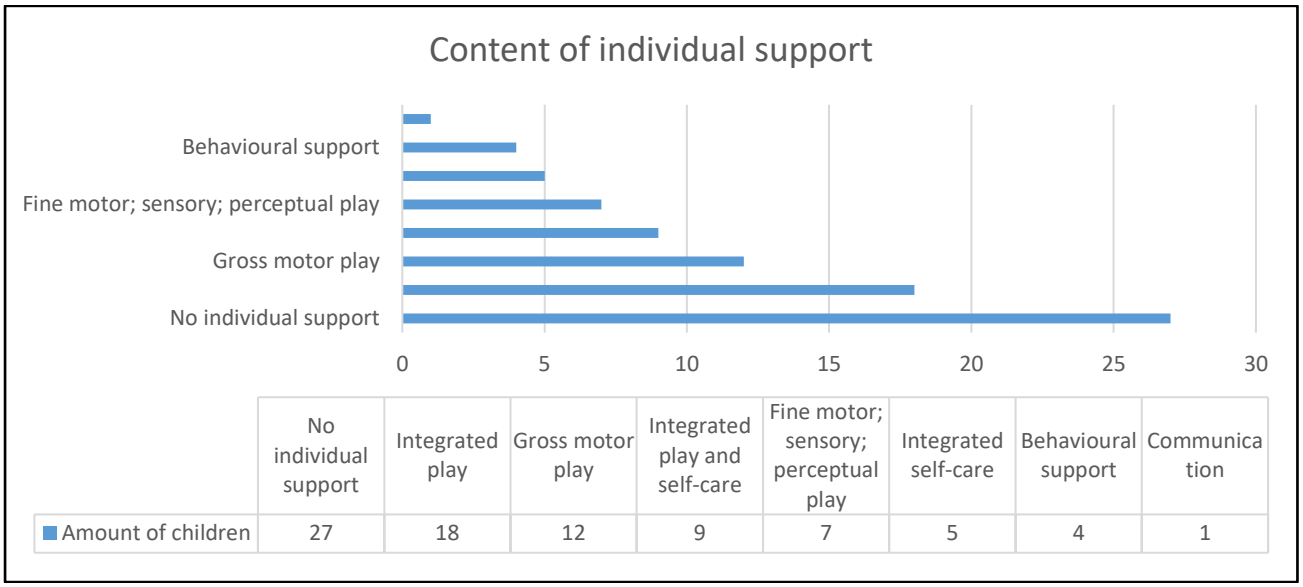
Structured group activities were those that made up the daily program. Some centres would have implemented only a few programs developed by the team, while others would have most of their daily program filled with the programs documented in this study. The analysis about the content of group support focused on how often a certain program was implemented or not, according to the number of children who had exposure to that specific program. Differences in groups, according to the composition in terms of functional abilities (e.g. mobile and non-mobile), were not taken into account.



n = 83

FIGURE 22: THE CONTENT OF EDUCATIONAL SUPPORT RENDERED IN GROUPS

The most commonly implemented interventions entailed making changes to the environment to optimize learning and implementing gross motor activities (65 children, 78% of the sample, in each group). This was followed by integrated self-care activities (73.5%) and activities designed to develop basic perceptual skills (73%). Other activities which were implemented on a regular basis – exposure ranging from 58 (70.0%) to 44 (53.0%) children – were sensory/art related activities, fine motor activities, activities involving music and dance as well as multi-sensory story telling. Activities to specifically address communication needs (42%) and the needs of children with physical disability (21.7% mobility; 19.3% positioning) were implemented for fewer children. Very few children formed part of a group where age appropriate ADL and social activities were implemented. No social-emotional discussion groups were facilitated by the WCED team. As the activities are ultimately implemented by the care worker - at a frequency not documented by the SCC staff - the frequency of each type of group intervention could not be recorded here.



	No individual support	Integrated play	Gross motor play	Integrated play and self-care	Fine motor; sensory; perceptual play	Integrated self-care	Behavioural support	Communication
Amount of children	27	18	12	9	7	5	4	1

n = 83

FIGURE 23: THE CONTENT OF SUPPORT RENDERED BY THE WCED TEAM ON AN INDIVIDUAL BASIS

For each child that received individual therapeutic input, the categories that applied were selected. It was found that 56 (67.5%) were seen by one or more team members on an individual basis. Most programs were centred on integrated play 18 (21.7%), gross motor play – 12 (14.5%) and a combination of integrated self-care and play – 9 (10.8%). Fine motor, sensory and perceptual activities were less frequently addressed in isolation (7), as were the case for self-care (5), behaviour (4) and communication (1) related needs.

The team was able to involve 22 (26.5%) of the children's parents/guardians in discussions on individual support.

5.3.3 Factors associated with improvement on the P scales

To allow for the calculation of the odds ratios, the relevant factors were dichotomised as follows:

- Language: Concordant meant that the home language corresponded to the language of instruction at the SCC.
- Medical condition: No chronic medical conditions were found in the individual files at the SCC.
- Independent mobility: Level I and level II on GMFCS scale.
- Effective communication: Levels I, II and III on the CFCS scale.
- Comprehensive support: Direct (individual and group) as well as indirect support from the team, as described in 5.2.1.1.
- Individual intervention: Direct support in the form of child-specific therapeutic intervention.

The percentage of those improving was greatest in those who received concordant language care, had no co-morbid medical conditions, were independently mobile, had effective communication, received comprehensive support and received individual attention. However, the odds ratios for all these independent variables included 1 and the z values were not significant (Table 32).

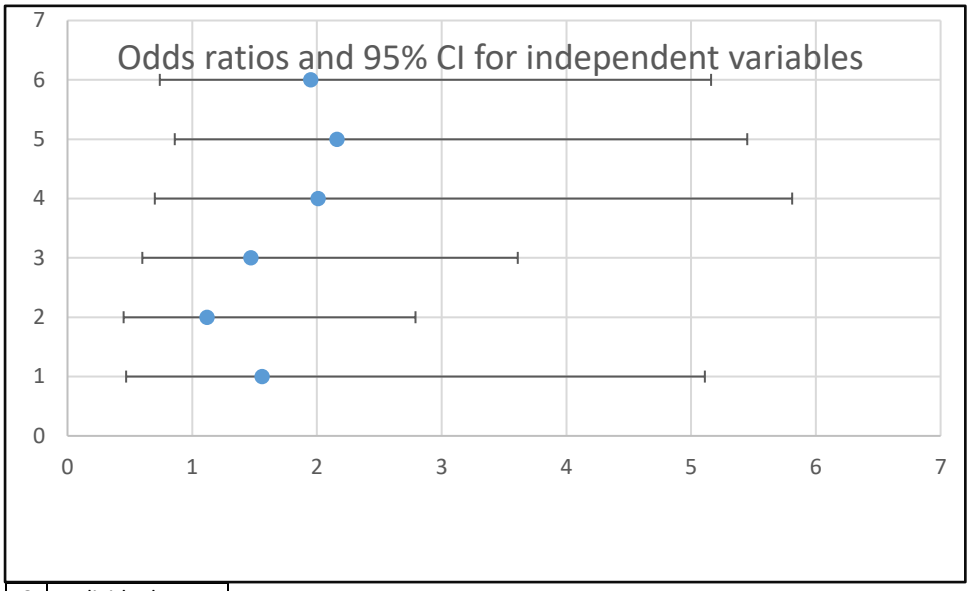
TABLE 32: ASSOCIATIONS BETWEEN DICHOTOMISED INDEPENDENT VARIABLES AND PROGRESS ON THE P SCALES

	Progress	N	%	N	%	Odds ratio	95% CI	Z	P value
Concordance of language	No	7	53.8.	6	46.2.				
	Yes	30	42.9.	40	57.1.	1.56	0.47 to 5.11	0.728	0.464
No chronic medical condition	Yes	13	46.4.	15	53.6.				
	No	24	43.6.	31	56.4.	1.12	0.45 to 2.79	0.242	0.809
Independent mobility	No	18	50.0.	18	50.0.				
	Yes	17	40.5.	25	59.5.	1.47	0.60 to 3.61	0.842	0.400
Effective communication	No	17	47.2.	19	52.8.				
	Yes	8	30.8.	18	69.2.	2.01	0.70 to 5.81	1.295	0.193
Comprehensive support	No	16	57.1.	12	42.9.				
	Yes	21	38.2.	34	61.8.	2.16	0.86 to 5.45	1.63	0.100
Individual intervention	No	13	56.5.	10	43.5.				
	Yes	24	40.0.	36	60.0.	1.95	0.74 to 5.16	1.345	0.175

There was no significant difference between the ages of the group that demonstrated improvement and those that did not (p=0.486) (Table 33).

Table 33: Association between age and progress on the P scales

	Mean Yes	Std.Dev. Yes	Mean No	Std.Dev. No	t-value	df	p	Valid N Yes	Valid N No
Age at first assessment	8.95	2.69	8.55	2.41	0.70	80	0.486	46	36



6	Individual intervention
5	Comprehensive support
4	Effective communication
3	Independent mobility
2	No chronic medical condition
1	Concordance of language

FIGURE 24: ODDS RATIOS FOR INDEPENDENT FACTORS ASSOCIATED WITH IMPROVEMENT IN P SCALE SCORES

The OR are depicted in Figure 24 and it can be seen that the ORs are all greater than 1 indicating that any effect of the presence of the factor increases the odds of improvement, although not significantly so. The odds are greatest for those receiving comprehensive support (5) and with the ability to communicate effectively (4) and children were twice as likely to show improvement, although this is not significant. The Confidence Intervals (CIs) were large.

5.4 Discussion

The sample was representative of the children registered with the WCED rural team in terms of age and gender as discussed in Chapter 4. The results are likely to be generalizable to this group of children.

5.4.1 Discussion on the approach and strategies for WCED intervention

The team's approach seemed to draw from most of those interventions reported in the literature. Sensory and environmental enrichment (including the organisation of classrooms), social interaction and the development of language as well as motor skills were addressed. It does seem, however,

that motor skills training involved more general training than that of preselected functional motor skills, according to individualised needs. It was also not evident whether group activities were designed specifically for children with physical disabilities as suggested in Chapter 3. Emphasis was placed on self-care activities and the intention to address domestic tasks and other everyday skills. This was seen but yet not implemented at large. How activities were adapted to accommodate individual needs have not been documented and this is important to consider in relation to guidelines for P scale assessment. The limited involvement of parents in individualised support were documented, but this item did not include interviews with regard to school placement, nor parental involvement in training on the content of support.

The team followed a holistic approach, mainly addressing educational needs by means of group intervention. Individual support was mostly additional to group support. Very few children did not have direct input from team members. This corresponds to what Geiger (2012) suggested in the context of SCCs in the WC - practical and hands on training of group activities are essential [53] instead of only off-site workshop type training. Therapeutic and educational services were not reported on separately - an indication of the intention to integrate the two entities – which correlates with what has been done around the world [26]. Neither was individualised support compartmentalized according to the different disciplines. This is often a paradigm shift for the WCED therapists whose focus, despite addressing medical and psychosocial needs in a holistic manner by promoting participation in life situations, may have been inclined towards rehabilitation rather than education.

The different dimensions of skills development are reflected in the content of group support, with no specific reference to the subject areas. Future documentation of group support should bear in mind different areas within the different subject areas. It is unclear how much emphasis is placed on a developmental approach in the content of individual support. This is probably because this sample was between the ages of five and 16 years old. Documenting early intervention strategies should form part of the content of individualised support. Yet the team's overall approach of inclusion through changing the environment, integration of therapy and educational services and involvement of direct support persons in all aspects of the daily program is well supported in international literature [11, 26, 41, 88].

The method of implementing support can be described as education of the direct support worker to enable engagement and participation of children with SPID in appropriate activities, in line with the QoL model [39]. Addressing structure and routine in the educational environment and the use of integrated activities is in line with the American Association on Intellectual and Developmental Disabilities (AAIDD) model [154] and resembles the constructs described to form the basis of learning in SPID [96].

Much of the referenced literature documents the nature of intervention for CSPID as being based around individualised support needs, with few group related activities found [41, 53, 73, 99, 106] and no documentation of comprehensive regimes [92, 95, 155]. This renders the results of this chapter significant. Programs were also multi-faceted, with the SCC environment taken into account.

Components of both group and individual support were documented. The content of group support included 14 items, of which classroom structure [73, 99], multisensory storytelling [106] and communication [53] correspond to the only group activities found in the literature. Self-care as a theme was also found in the literature [41, 73]. Exposure to activities based purely around communication seem to be low, but based on the results in terms of the nature of support, basic communication strategies were possibly integrated and embedded within the other group activities. Similar to recommendations from existing literature, the focus seemed to be on inclusion practices and creating a responsive environment to improve participation in communication opportunities [53, 75]. Few children reportedly received any programs related to socio-emotional support from the WCED team. It can be that this need was addressed more indirectly via empowerment of SCC staff, or that the SCCs had their own discussion and support groups in place. This should be investigated further. Individualised support of this nature also did not reflect under the content of individual support, as it was not documented in the centre files – due to the sensitive nature of the information. Challenging behaviour was not addressed in a group context, but could be seen to be indirectly addressed via structuring of the classroom, classroom activities and individually via engagement in appropriate activities [100]. This may be a gap in the programme that needs to be addressed in the future.

The way in which group support strategies were reported led to results that portrayed a snapshot at the time of data entry. More children would have had exposure to programs developed and implemented in 2014 than those programs implemented more recently. Therefore, the limited exposure to age appropriate activities could be an indication that the team first focused on activities for the bulk of the children between ages six and fourteen. The need in terms of future program development, especially for adolescents, is thus portrayed.

It became apparent that almost three quarters of the sample received individual support from team members, mainly centred on integrated play and self-care. This reflected that communication, positioning, motor skills, hand function and perceptual skills were embedded into these sessions. Individual participation in gross motor play was frequently addressed, followed by ensuring participation in fine motor and perceptual activities. Communication participation was seldom addressed in isolation. This approach is supported in the literature, where it is advised that intervention takes place in a “contextualized setting” rather than withdrawing children from “scheduled routines”[43]. It was also documented that most children with SPID who used AAC, used “typically manual signs” [43], which implies that communication strategies could have been implemented in group fashion. Alternately, this could simply be due to the manner in which programs were phased in, possibly indicating a need to be addressed in future.

Parental involvement was limited, probably due to various logistical difficulties in service delivery and/or transport and time away from work on the part of the parent. Given the utmost importance of family involvement, a definite strategy to improve the involvement of parents or guardians is necessary.

The difficulties in service delivery are reflected in the relatively low frequency of centre visits recorded between assessments. This may be contributable to the growth in service delivery sites,

from 12 to 20 SCCs between 2014 and 2017. This is a concern and has definite implication on the amount of direct support the team can deliver, even in groups. The need for close monitoring of services with impact on the individual, in order to determine the optimal SCC: team ratio becomes apparent. Given the large travelling distances and rapid increase as children are identified in every town, it is expected that, if this ratio is similar to the ratio for the teams in the metropolitan areas, the approach and strategies of service delivery will not be comparable.

The limited centre visits also highlights the need to collaborate closely with SCCs and implement strategies in order to monitor the frequency of the actual execution of the programs. The influence of the attitudinal environment will be crucial to consider and might be one of the reasons that this study was unable to identify significant factors related to improvement.

5.4.2 Discussion of factors investigated

The independent variables of age (personal), absence of associated medical conditions (body structure and function) and functional abilities (activities and participation) were the intrinsic factors under investigation [1]. The environmental factors examined were the independent variables of concordance between home and teaching language and the nature of support (comprehensive support package and individual support – see 5.2.1.1). Each of these factors was found to increase the odds of improvement, but the confidence intervals were large and the association was not significant. The lack of significance might be due to the relatively small sample size and this pilot study suggests that a large-scale study, including all children registered with the team, may be warranted and provide a better indication of which children characteristics and which treatment approaches are likely to be associated with improvement. For example, effective communication was found to be the most likely intrinsic indicator of increased performance, and if proven in a definitive study, this ability could be targeted more during support sessions. The support provided by other WCED teams does not necessarily correspond to what was described in this study and could possibly be more discipline specific. If further research were to support the trend that integrated, comprehensive support increased the odds of improvement, this evidence could be used to inform the future approach to support by all the WCED teams and, possibly, other teams employed by the DoE to provide support to children with SPID.

The broad nature of the study design also allowed for too many confounding variables, which hampered the accurate detection of correlates of change. These included the large variations in the different settings, variations in the implementation of support as well as variations in the duration and frequency of interventions. Learning and developing skills in SPID are only possible in an intensive relationship with direct support staff and constructive interaction with the environment [156]. It is possible that the attitudinal environment of SCC cooperation and stakeholder collaboration [16, 102] could have played a role in the outcome. The additionally available therapy services also could have affected the outcome. Time constraints and limitations in person centred planning and support are universal challenges, which would ultimately influence personal outcomes. Unravelling the elements of success of a program from contextual factors remains a challenge too [157].

In terms of the variables under investigation, language concordance might not have shown to make a difference due to the fact that many children would have been at a pre-linguistic stage, where non-

verbal language would be the important factor to consider [75]. Through the facilitation of sensitivity and responsivity of care workers and parents to non-verbal cues, congruence between home language and language of instruction might prove to be less of a factor in children with PID [41].

Medical conditions cause absence and decreased participation, but to varying degrees [66]. Refining the construction of this variable should be considered.

The ability to interact is an important determinant of participation [129]. Especially the first six level descriptors of the P scales depict different stages in the ability to interact, irrespective of the underlying health condition, impairment or functional skills deficit. The expected finding was that children with lower P scale scores would not perform as well as their higher functioning peers. In this study, children progressed irrespective of their P scale score. The expectations regarding the age and communication ability [5, 158] of the children were not met. Two possibilities are worth considering:

- The severity of the intellectual disability [159] has not been taken into account, which would differentiate between profound and severe ID, and lead to a more homogenous sample. Turner & Alborz (2003) state that the intellectual impairment itself could be the "most significant predictor of academic attainment", probably more specifically in SID, measured by the upper part of the P scales [132].
- Activities which promoted participation on a large scale were not performed in SCCs prior to the appointment of the team [53]. With the introduction of a large variety of educational activity throughout the day, children were able to indicate their capabilities. The reported improvement in performance may not have been a true improvement but a reflection of the introduction of a programme that allowed the capabilities to be more accurately monitored. In other words, the measurement became more accurate over time, rather than the children improving their performance. Repetitive measures, after a certain period since first exposure to educational activities, could perhaps have yielded different results.

It was to be expected that mobility would not be correlated to change in educational performance, since accommodation was made for children with limited mobility. As programs are increasingly tailored to accommodate children with severe physical disabilities, the expectations would be to find even less of an impact of independent mobility of educational performance.

5.4.3 Strengths, limitations and recommendations

This part of the study allowed for better insight into the approaches and support strategies followed by an inter-professional team in delivering educational services. Managing and monitoring service delivery can be made more efficient by reporting and comparing intervention amongst different teams. The knowledge acquired can be applied in the refinement of reporting templates, yet definite differences in service delivery strategies is expected to exist between rural and metropolitan based teams.

Although the research setting is well described, more attention is needed with regard to the heterogeneous nature of the different SCC settings. Multivariate models are needed to inform best daily practice [131, 133], but future longitudinal studies should also take into account the

heterogeneous nature surrounding the interventionist. The team, as an entity, is described as the interventionist, but the large variance in the number of centre visits was a cause of disparity with regard to the implementation of support. As strategies were ultimately implemented via different staff members who were trained by the team, there is a need for documentation on the level of the direct support worker. These should include the intensity and duration of support, which were not documented. Neither was the degree of individual support in terms of care worker: child ratio reported. Other incongruences also existed between different SCC settings and none of these factors was controlled for during the study.

The P scales as a measurement of educational performance were found to be valid and reliable in this research setting (see Chapter 4). However, variables will need to be well controlled for when conducting studies of such a pragmatic nature.

The study did not detect any single factor associated with change in performance over a period of more than one year. One reason can be the large number of confounding variables discussed above. However, bias should be considered due to the small sample size and the fact that inter- and intra-rater reliability could not be determined. The small sample size was due to the large amount of missing data on the classification system scores, used to determine effective communication and independent mobility. These limitations in the study methodology could have led to bias and the resultant under powering of the study.

Still, there were some indications that certain factors were associated with improvement, although not significant. Effective communication and comprehensive support stood out as possible indicators of improved performance. However, there are many other possible indicators identified in the literature, which are well worth exploring.

Chapter 6. Conclusion

6.1 Overview of the chapters

One of the outcomes of this study was the identification of the characteristics of children with SPID in SCCs in rural parts of the WC in receipt of educational support. About 500 children attended one of 20 SCCs during the period of the study. From the literature, it is known that SCCs are community-based organisations, mostly poorly resourced and with few staff who are qualified educators.

Most children were from the age group 6-14 years and although much of the information on socio-economic conditions was unavailable, previous studies show that they are from vulnerable families who receive limited support. The lack of a definite medical diagnosis available to the team members limits the scope of this study in terms of reporting on prevalence estimates. Yet the most frequent co-morbid health conditions were CP, behavioural disorders and epilepsy. Access to therapeutic services, including assistive devices, was established. However, not all received instruction in their home language at the specific SCC. The results from functional and participation level assessments highlighted the fact that there are distinct groups with distinct support needs in terms of daily functioning. Transport needs were mostly met for those already in attendance, yet a number of children dropped out of the centres. The reasons have not been explored in this study, but it will be well worth looking into it. Most heartening was the fact that the team was able to facilitate more suitable placement in schools for a number of candidates.

These were the broad characteristics of the population, from which a sample was used to establish the validity of an educational outcome measure named the P scales. The COSMIN checklist was applied to validate the P scales as a monitoring tool in this specific context. Content and face validity were accepted to have been established in the UK, from where it originated. The P scales were found to be responsive and detected change across all subject areas, over a minimum time of one year between assessments. Internal consistency was high, but less so in the higher functioning individuals where it allowed for discrimination between curricular areas. It is, therefore, considered a reliable outcome measure, if used within the context of the rural team and using a similar training and score allocation methodology. Definite convergence was found to exist between the subject area of English Speaking and communication abilities (according to CFCS). Convergence was less clear in the performance of those with moderate to severe physical disability, affecting both mobility and manipulative function. Yet, the scales generally demonstrated reliability in distinguishing between the attainments of high- and low-achieving children, across all subject areas. The P scales showed concurrent validity with the Vineland Adaptive Behaviour Scales II, with the highest correlation found between English Speaking and interpersonal relationships. This is significant in that the P scales are sensitive despite lower communication abilities. Despite being a valid outcome measure, found to be useful by professionals in the field, challenges remain in terms of the feasibility of routine use.

The utility of the P scales for research purposes was also explored. Apart from providing a detailed account of the intervention strategies of the team, the aim was to identify possible variables, which could in future be examined as correlates of change in the educational participation of children with

SPID. The current trend in rehabilitation research is to consider multiple factors, both intrinsic and environmental, and this guided the identification of factors to consider. Amongst the factors of age, associated medical conditions, language concordance, independent mobility or individual intervention, the ability to communicate effectively were found to be the most likely intrinsic indicator. A comprehensive support package was the most likely environmental indicator of educational performance. Yet the lack of congruence between settings, duration, intensity and implementation of support, contributed towards the inability to find significant indicators. Despite the limited results, the challenges identified provide valuable pointers for future research in the field.

In terms of service delivery, the team's overall approach of inclusion in all aspects of the daily program is well supported in international literature. The nature and content of support were not only comparable to international trends, but more components were documented than what was found in the literature. The frequency of the team's visit to the centres is a source of concern and monitoring of service delivery is necessary to optimize support. Most importantly, what was confirmed was that irrespective of all these factors and irrespective of their abilities, children with SPID appear to have the potential to learn a broad range of skills.

6.2 Strengths and limitations of the study

The strength of this study lies in the detail in which the participants, their functional abilities and educational performance were defined, using standardised outcome measures (classification systems and VABS II). This added to both the internal and external validity of the study. Although a detailed outline of the nature of support was provided, many threats to internal validity existed due to the shortcomings of accurately portraying frequency, intensity and duration. Treatment fidelity was shown in the delivery of support from the team, but not in the everyday delivery of support from direct care workers.

The finding that the P scales is a valid and reliable outcome measure for this group of children with SPID is an important step towards ensuring evidence-based practice in the delivery of educational support. The validation of this outcome measure in a contextualised setting added to the social validity of the study and through the accurate description of the participant characteristics, generalisation to the larger South African population becomes a possibility.

At the time of the study, only one of the four teams in the province was using the P scales routinely and, based on that, the P scales are perceived to be complex and cumbersome. Accurate interpretation of the behaviour of a child with SPID is dependent on how well the child is known. With a large caseload, it might take a while before team members feel confident enough to allocate a score. However, despite limited experience on the part of most provincial team members, the majority felt it was worthwhile and continuous training, implementation, moderation and re-evaluation were warranted.

Caution is needed when interpreting the satisfactory responsiveness of the P scales and the positive outcomes related to the validity of this assessment tool. The possible scenario exists that, due to the

previous void of educational stimulation, the second measurement portrayed a child's true capabilities rather than improved performance. In addition, the limited parameters in terms of assessment protocols within an environment where structured activities were not necessarily the norm, it is unlikely that a distinction was made between the constructs of capability and performance.

Despite the challenges experienced, this study lays the foundation for solid future research. More indicators can be explored by using a larger sample and improved control of confounding variables. Although many other factors were identified during the literature search, the role and importance of parental involvement stands out as an extremely important factor to consider in future research, service delivery and support [160].

6.3 Implications and recommendations

6.3.1 Future directions for assessment

Ultimately, the implications of this study need to benefit children with SPID and their direct families. Effective assessment strategies, which measure educational performance in such a fashion that it portrays learning for this group of learners, should guide professionals in planning effective intervention strategies. In this way optimal skills development can take place, decreasing the amount of dependence and increasing the quality of life for these learners and their families.

The results of the study showed that the P scales have great potential in achieving this objective. Effective implementation of the P scales as a routine outcome measure will, however, require a will to do so from policy makers and an active drive from provincial departments. It would also be advisable to educate parents on what these scales represent and how they demonstrate their child's progress. In this way parents could become more involved in seeing what has been achieved as well as sharing their views on priority areas to be addressed. Service delivery would have to be strategized in such a fashion to allow sufficient contact between professional, learner, parent and care worker [150].

The P scales can be rolled out alongside the newly developed Learning Programme for learners with SPID. The advantage to service providers is a proven way of measuring the efficacy of educational support to children [51]. This study demonstrated that it can be implemented efficiently in SCCs, but, due to its development in a fully inclusive environment, it also has the potential to be trialled in special schools. This would ensure a continuum of support to the child along his/her pathway of learning.

To become standard protocol, the instrument will have to be validated within a larger context. Training institutions should be invited to assist with training administrators, to standardize the assessment process and to assist in the development of guidelines for making accommodations. CPD accreditation for professionals would be a prerequisite.

6.3.2 Future directions for educational support

Information gained from the database of routinely collected information indicates that there is a need for instruction, as well as learning and support materials, to be available in both Afrikaans and IsiXhosa. It is important that teams and centre staff ensure social support is in place for children and their families. Given the high number of co-morbid conditions, presence of chronic medical conditions and use of chronic medication, it is important for SCCs and teams to work in close collaboration with their Community Based Support Co-ordinator (Western Cape Department of Health), to ensure optical medical support is rendered. It is imperative that rehabilitation services from DoH continues and that the services of other therapists are utilised optimally. This is important given the entirely different focus and scope of services rendered by educational therapists. Regular interdepartmental communication between colleagues on both the operational and decision-making level is necessary to ensure that every child receives the individualized therapeutic support needed. It is recommended that the eco-systemic approach be applied to the context of teaching and learning and that the parents and communities are included in the decision making process.

This study has confirmed that children can learn, irrespective of their level of intellectual disability. To optimize learning, it is important, however, to know and address relevant factors. This study identified the difficulties of determining these factors. Close collaboration with researchers and training institutions is necessary to achieve optimal impact in a novel field where resources are limited. This study demonstrated the potential of the P scales as a participation level assessment tool in research. However, documenting the fidelity of implementation is an essential requirement of quality research. This would necessitate ground level access to information and the development of guidelines for implementation and documentation of support strategies. This would in turn help to standardize implementation on the level of service delivery and ultimately benefit the learner with SPID on his or her path of lifelong learning.

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Appendices

Appendix A: Data Extraction Form

CODEBOOK

Blue = Questions added or removed

Green = Changes made to response options

1.What is the child's unique number? (Identification number)
2.What is the child's surname?
3.What is the child's given name?
4.What is the child's date of birth?
5.What is the child's home address?
6.To which centre of care does the child go? (7. CSPID team linked to centre removed)
7.What is the child's home language?
8.What is the child's gender?
9.What is the structure of the child's family?
"Unknown" added as response option
10.Family Income category (grants included)
11.Does the child receive a grant?
12.How does the child get to the care centre?
"Transport is primary barrier" added as a response option
13.Does the child have a wheelchair?
14.Does the child have a buggy?
15.Does the child have splints?
16.Does the child have a standing frame?
17.Does the child have a hearing aid?
18.Does the child wear glasses?
19.Does the child currently use an AAC system?
"no, but need one " replaced with "no, but need assessment"
20.Which level of educational support is needed?
21.What is the language of learning and teaching (LOLT) at the centre that the child attends?
22.Does the home language of the child correspond to the language of learning and teaching (LOLT) available to the child at the centre?
23.Is there a specific diagnosis (ICD 10) for this child available in the files at the specific centre?
If no, jump to 25
24.What is the most applicable diagnosis of the child according to ICD 11, as diagnosed by a medical practitioner? Please use specific code.
25.What is the child's probable health condition?
26.What is the child's co-morbid probable health condition?
27.What is the aetiology of the child's health condition?
28.What associated (probable) chronic or recurring medical conditions does the child have?
"None indicated" added as response option
29.What type of CHRONIC medication does the child receive?
30.Which medication does the child take? If more than one, please enter one answer per

question. (1st medication)
31.Which medication does the child take? If more than one, please enter one answer per question. (2nd medication)
32.What kind of medical intervention did the child receive in the past 12 months?
33.What type of therapeutic intervention does the child receive from the Department of Health?
34.Does the child receive other therapeutic services?
Item 32 Therapeutic intervention (non CSPID) were split into items 33 and 34.
35.What other services are available at the centre?
36.Has the child's IQ been assessed? (added in order to determine if ID)
- yes (yes)
- no (no) If this response, jump to 39

37.What date was the IQ assessed? (added)
38.In what category is the child's IQ? (added)
- <70 (ID)
- 70+ (Not_ID)

39.Has adaptive functioning been tested using VABS II? (added)
- yes (yes)
- no (no) If this response, jump to 49

40.What is the adaptive functioning score for "gross motor" according to VABS II? (added)
41.What is the adaptive functioning score for "fine motor" according to VABS II? (added)
42.What is the adaptive functioning score for "communication- receptive" according to VABS II? (added)
43.What is the adaptive functioning score for "communication – expressive" according to VABS II? (added)
44.What is the adaptive functioning score for "interpersonal relationships" according to VABS II? (added)
45.What is the adaptive functioning score for "play and leisure" according to VABS II? (added)
46.What is the adaptive functioning score for "personal and daily living" according to VABS II? (added)
47.On which date were the Classification Systems and support needed for self care assessed for the first time? (added)
48.What is the child's level according to the Manual Ability Classification System?
Removed "unknown" as a response option
49.What is the child's level according to the Gross Motor Function Classification System?
Removed "unknown" as a response option
50.What is the child's level according to the Communication Function Classification System?
Removed "unknown" as a response option
51.What is the level of support needed for feeding at first assessment?
Removed "unknown" as a response option
52.What is the child's level of support needed for cup drinking at first assessment?
Removed "unknown" as a response option
53.What is the child's level of support needed to dress and undress him or herself at first assessment?
Removed "unknown" as a response option
54.What is the level of support needed by the child when brushing teeth at first

assessment?

Removed “unknown” as a response option

55.What is the level of support needed by the child in terms of toileting at first assessment?

Removed “unknown” as a response option

56.What is the child's Self Care score at first assessment?

57.Is the child between the ages of 5 and 16 years? (added to indicate if P scale assessment were applicable)

- no (no) If this response, jump to 64
- yes (yes)

58.Were there P scale scores assigned for this child? (added to indicate if P scale assessment were done)

- yes (yes)
- no (no) If this response, jump to 64

59.On which date were the p-scales evaluated for the first time?

60.What is the child's p-scale for 'English Speaking' at time of first assessment?

Removed “unknown” as a response option

61.What is the child's p-scale for 'English Listening' at the first assessment?

Removed “unknown” as a response option

62.What is the child's p-scale for 'Using and Applying Mathematics' at the first assessment?

Removed “unknown” as a response option

63.What is the child's p-scale for 'Physical Education' at the first assessment?

Removed “unknown” as a response option

64.Was the child assessed for a second time? (added in order to skip intervention for those with only one assessment or not in centre any more)

- yes (yes) If this response, jump to 66
- no (no)

65.What happened to the child who is not at the centre on second assessment? (added)

- Deceased (Deceased). If this response, jump to 91
- At home (At_home). If this response, jump to 91
- Temporarily out of centre (Temporarily_out_of_centre). If this response, jump to 91
- Relocated to other town (Relocated_to_other_town). If this response, jump to 91
- Relocated to other SCC (Relocated_to_other_SCC). If this response, jump to 91
- Unknown (unknown). If this response, jump to 91
- Still in centre (in_centre). If this response, jump to 91
- ECD inclusion (ECD_inclusion)
- Special school (Special_school)
- Mainstream school (Mainstream_school)

66.What was the nature of support the child received from CSPID team? (CSPID intervention were split into items 66 to 70)

- Individual program (Individual_program). If this response, jump to 68
- Structured group activity (Structured_group_activity)
- Indirect caregiver training (Indirect_caregiver_training). If this response, jump to 70
- Individual and group (Individual_and_group)
- All of the above (All_of_the_above)
- Inclusive support (Inclusive_support). If this response, jump to 71
- No support (No_support). If this response, jump to 91

67.What is the content of the activities, developed by the team, for the child or the group (in which the child is exposed to these activities)?

- positioning (positioning)

- mobility (mobility)
- gross motor (gross_motor)
- fine motor (fine_motor)
- sensory including art (sensory_art)
- basic perceptual and pre-perceptual (basic_pre-perceptual)
- communication (communication)
- multi-sensory story telling (multi_sensory_story_telling)
- social-emotional (social_emotional)
- integrated self care (integrated_self-care)
- music and dance (music_and_dance)
- age appropriate ADL (age_appropriate_ADL)
- age appropriate social (age_appropriate_social)
- structure and function (structure_function)

68.What was the content of individual support from the team?

- gross motor (gross_motor)
- fine motor, sensory and basic perceptual (fm_sens_perc)
- communication (communication)
- integrated play (integrated_play)
- no individual support (no_individual support)
- Inclusive practices (inclusive_practices_)
- Integrated self care (integrated_self_care)
- behaviour (behaviour_)
- integrated play and self-care (integrated_play_and_self_care)

69.How many times did the child have direct contact, either individually or in a group, with one or more team members? (assign a 0 if no evidence of contact in folder)

70.How many times did the team visit the centre in the time period between first and second assessment?

71.Did the team meet with the parent or guardian of the child to discuss individual support? (added)

- yes (yes)
- no (no)

72.Was there a change in the level of any of the three classification systems (MACS, GMFCS, CFCS)? (added)

- yes (yes)
- no (no) If this response, jump to 77

73.If the classifications of gross motor, manual ability and/or communication has changed, on which date did you assess this change?

74.What is the child's new MACS classification on second assessment?

75.What is the child's new GMFCS classification on second assessment?

76.What is the child's new CFCS classification on second assessment?

77.Was the level of support needed for self-care activities re-assessed? (added)

- yes (yes)
- no (no) If this response, jump to 83

78.What is the level of support needed for feeding at second assessment?

79.What is the child's level of support needed for cup drinking at second assessment?

80.What is the child's level of support needed to dress and undress him or herself at second assessment?

81.What is the level of support needed by the child when brushing teeth at second assessment?

82.What is the level of support needed by the child in terms of toileting at second

assessment?

83.What is the child's score for support needed in terms of self-care on second assessment?

84.Is the child between the ages of 5-16 years at time of second assessment? (added)

- yes (yes)
- no (no) If this response, jump to 91

85.Have the P scale scores been reviewed? (added)

- yes (yes)
- no (no) If this response, jump to 91

86.What date was the P scale score reviewed?

87.What is the child's p-scale for 'English Speaking' at second assessment?

88.What is the child's p-scale for 'English Listening' at the second assessment?

89.What is the child's p-scale for 'Using and Applying Mathematics' at the second assessment?

90.What is the child's p-scale for 'Physical Education' at the second assessment?

91.Is absence a concern with regards to this child?

- yes (yes)
- no (no)
- unknown (unknown)

Appendices B1-3 Classification Systems

Appendix B1: Gross Motor Function Classification System

LEVEL I	Walks without limitations
LEVEL II	Walks with limitations
LEVEL III	Walks using a hand-held mobility device
LEVEL IV	Self-mobility with limitations; may use powered wheelchair
LEVEL V	Transported in a manual wheelchair

Appendix B2: Manual Ability Function Classification System

LEVEL I	Handles objects easily and successfully
LEVEL II	Handles most objects but with somewhat reduced quality and/or speed of achievement
LEVEL III	Handles objects with difficulty; needs help to prepare and/or modify activities
LEVEL IV	Handles a limited selection of easily managed objects in adapted situations
LEVEL V	Does not handle objects and has severely limited ability to perform even simple actions

Appendix B3: Communication Function Classification System

LEVEL I	Effective Sender and Receiver with unfamiliar and familiar partners
LEVEL II	Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners
LEVEL III	Effective Sender and Receiver with familiar partners
LEVEL IV	Inconsistent Sender and/or Receiver with familiar partners
LEVEL V	Seldom Effective Sender and Receiver even with familiar partners

Appendices C1-3: P scales

Appendix C1: Extracts from P scale for English (Speaking and Listening)

P1(i)	Pupils encounter activities and experiences. They may show simple reflex responses, for example, startling at sudden noises or movements. Any participation is fully prompted.
P1(ii)	Pupils show emerging awareness of activities and experiences. They may have periods when they appear alert and ready to focus their attention, for example, attending briefly to interactions with a familiar person. They may give intermittent reactions.
P2(i)	Pupils begin to respond consistently to familiar people, events and objects. They react to new activities. They begin to show interest in people, events and objects, for example, smiling at familiar people. They accept and engage in coactive exploration.
P2(ii)	Pupils begin to be proactive in their interactions. They communicate consistent preferences and affective responses, for example, reaching out to a favourite person. They recognize familiar people, events and objects. They perform actions, often by trial and improvement, and they remember learned responses over short periods of time. They cooperate with shared exploration and supported participation.
P3(i)	Pupils begin to communicate intentionally. They seek attention through eye contact, gesture or action. They request events or activities, for example, pointing to key objects or people. They participate in shared activities with less support. They sustain concentration for short periods. They explore materials in increasingly complex ways. They observe the results of their own actions with interest. They remember learned responses over more extended periods.
P3(ii)	Pupils use emerging conventional communication. They greet known people and may initiate interactions and activities. They can remember learned responses over increasing periods of time and may anticipate known events. They may respond to options and choices with actions or gestures. They actively explore objects and events for more extended periods. They apply potential solutions systematically to problems.

P4 Speaking	Pupils repeats, copy and imitate between 10 and 50 single words, signs or phrases or use a repertoire of objects of reference or symbols. They use single words, signs and symbols for familiar objects and to communicate about events and feelings.
P4 Listening	Pupils demonstrate an understanding of at least 50 words, including the names of familiar objects. Pupils respond appropriately to simple requests which contain one key word, sign or symbol in familiar situations, for example, 'Get your coat', 'Stand up' or 'Clap your hands'.
P5 Speaking	Pupils combine two key ideas or concepts. They combine single words, signs or symbols to communicate meaning to a range of listeners, for example, 'Mummy gone' or 'more drink'. They make attempts to repair misunderstandings without changing the words used, for example, by repeating a word with a different intonation or facial expression. Pupils use a vocabulary of over 50 words.
P5 Listening	Pupils respond appropriately to questions about familiar or immediate events or experiences, for example, 'Where is the ball?', 'What are you doing?', 'Is it yellow?' They follow requests and instructions containing at least two key words, signs or symbols, for example, 'Put the spoon in the dish', 'Give the book to Johnny'.
P6 Speaking	Pupils initiate and maintain short conversations using their preferred medium of communication. They ask simple questions to obtain information, for example, 'Where's the cat?. They can use prepositions, such as 'in' or 'on', and pronouns, such as 'my' or 'it', correctly.
P6 Listening	Pupils respond to others in group situations, for example, taking turns appropriately in a game such as 'Pass the parcel'. They follow requests and instructions with three key words, signs or symbols, for example, 'Give me the little red book'.

P7 Speaking	Pupils use phrases with up to three key words, signs or symbols to communicate simple ideas, events or stories to others, for example, 'I want big chocolate muffin'. They use regular plurals correctly. They communicate ideas about present, past and future events and experiences, using simple phrases and statements, for example, 'We going cinema on Friday'. They contribute appropriately one-to-one and in small group discussions and role play. They use the conjunction and to link ideas or add new information beyond what is asked.
P7 Listening	Pupils listen, attend to and follow stories for short stretches of time. They follow requests and instructions with four key words, signs or symbols, for example, 'Get the big book about dinosaurs from the library'. They attend to, and respond to, questions from adults and their peers about experiences, events and stories, for example, 'Where has the boy gone?'.
P8 Speaking	They link up to four key words, signs or symbols in communicating about their own experiences or in telling familiar stories, both in groups and one-to- one, for example, 'The hairy giant shouted at Finn'. They use an extensive vocabulary to convey meaning to the listener. They can use possessives, for example, 'Johnny's coat'. They take part in role play with confidence. They use conjunctions that suggest cause, for example, 'cos,' to link ideas.
P8 Listening	Pupils take part in role play with confidence. Pupils listen attentively. They respond appropriately to questions about why or how, for example 'Why does a bird make a nest?', 'How do we copy this picture?'

Appendix C2: Extracts from P scales for Physical Education

P1(i)	Pupils encounter activities and experiences. They may be passive or resistant. They may show simple reflex responses, *for example startling at sudden noises or movements*. Any participation is fully prompted.
P1(ii)	Pupils show emerging awareness of activities and experiences. They may have periods when they appear alert and ready to focus their attention on certain people, events, objects or parts of objects *for example, turning briefly towards fast-moving group activity*. They may give intermittent reactions *for example, sometimes turning away from people or objects moving close to them.*
P2(i)	Pupils begin to respond consistently to familiar people, events and objects. They react to new activities and experiences *for example, showing surprise when moving into an outdoor environment*. They begin to show interest in people, events and objects *for example, patting at footballs brought towards them*. They accept and engage in coactive exploration *for example, moving about in the swimming pool with the support of a member of staff*.
P2(ii)	Pupils begin to be proactive in their interactions. They communicate consistent preferences and affective responses *for example, smiling in dance or movement activities.* They recognise familiar people, events and objects *for example, gesturing or vocalising in a particular way on arrival at the poolside*. They perform actions, often by trial and improvement, and they remember learned responses over short periods of time *for example, pushing away a ball when it is repeatedly rolled towards the.* They cooperate with shared exploration and supported participation *for example, being guided in creating patterns of movement.*
P3(i)	Pupils begin to communicate intentionally. They seek attention through eye contact, gesture or action. They request events or activities *for example, pointing to a particular piece of PE equipment.* They participate in shared activities with less support. They sustain concentration for short periods They explore materials in increasingly complex ways *for example, tapping one item of equipment with another*. They observe the results of their own actions with interest *for example, dabbling their hands in the swimming pool and attending to the effects*. They remember learned responses over more extended periods *for example, bouncing up and down on a trampette*.

P3(ii)	Pupils use emerging conventional communication. They greet known people and may initiate interactions and activities *for example, pushing a ball towards a peer or adult.* They can remember learned responses over increasing periods of time and may anticipate known events *for example, beginning to move when the music starts.* They may respond to options and choices with actions or gestures, *for example, moving towards one outdoor activity rather than another*. They actively explore objects and events for more extended periods *for example, moving around a space and encountering a range of objects or obstacles*. They apply potential solutions systematically to problems *for example, reaching out a foot or a hand to intercept a moving ball.*
P4	Pupils' movement patterns are established and they perform single actions *for example, rolling, running, jumping or splashing.* They respond to simple commands *for example, 'stop'.* They recognise familiar pieces of equipment *for example, a ball or hoop.* They show awareness of cause and effect *for example, knocking down skittles*.
P5	Pupils link two actions in a sequence *for example, crawling and walking, or climbing and jumping*. They follow simple instructions although they may need the support of symbols or other prompts. They explore a variety of movements and show some awareness of space. They understand some basic concepts *for example, taking big and little steps in movement activities or placing big and small balls in different baskets*. They take turns with a partner or in a small group. They recognise and collect, on request, familiar pieces of equipment *for example, a mat to lie on or a hoop to jump into.*
P6	Pupils work in pairs and in small groups cooperatively, although they may need support to follow instructions and keep on task. They move in a variety of ways *for example, slowly and quickly*. They link movements in a simple sequence, although they may require support to do this. They recognise small and large apparatus and use it with some basic control. They throw and kick a ball, but lack direction.
P7	Pupils express themselves through repetitive and simple sequences and movement patterns. Their control and coordination skills are developing *for example, they kick a ball towards a target or throw a ball to a partner.* They listen to instructions and stop and start with some accuracy. They work closely in pairs, trios or small groups. They share and wait their turn. They are aware of the changes that happen to their bodies when they are active.

P8	Pupils move with some control and coordination *for example, they travel under and over climbing equipment.* They follow and imitate sequences and patterns in their movements. They use small and large apparatus safely. They are aware of space, themselves and others. They play simple games and may require support to keep score and follow game rules. They recognise the changes that happen to their bodies when they are active.

Appendix C3: Extracts from P scales for Using and Applying Mathematics

P1(i)	Pupils encounter activities and experiences. They may show simple reflex responses, *for example, startling at sudden noises or movements.* Any participation is fully prompted."
P1(ii)	Pupils show emerging awareness of activities and experiences. They may have periods when they appear alert and ready to focus their attention, *for example,* grasping objects briefly when they are placed in their hand. They may give intermittent reactions, for example, sometimes showing surprise at the sudden presence or absence of an event or object.
P2(i)	Pupils begin to respond consistently to familiar people, events and objects. They react to new activities for example, becoming excited or alarmed when a routine is broken. They begin to show interest in people, events and objects, *for example,* tracking objects briefly across their field of awareness. They accept and engage in coactive exploration, for example, lifting objects briefly towards the face in shared investigations].
P2(ii)	Pupils begin to be proactive in their interactions. They communicate consistent preferences and affective responses, *for example,* showing a desire to hold a favourite object. They recognize familiar people, events and objects, for example, looking towards their own lunch box when offered a selection They perform actions, often by trial and improvement, and they remember learned responses over short periods of time for example, repeating an action with a familiar item of equipment. They cooperate with shared exploration and supported participation, for example, handling and feeling the texture of objects passed to them.
P3(i)	Pupils begin to communicate intentionally. They seek attention through eye contact, gesture or action. They request events or activities, *for example,* pushing an item of equipment towards a member of staff. They participate in shared activities with less support. They sustain concentration for short periods. They explore materials in increasingly complex ways, for example, banging or rubbing objects together. They observe the results of their own actions with interest, for example, as they throw or drop objects on to different surfaces. They remember learned responses over more extended

	periods, for example, remembering how to activate a pop-up object from a previous lesson.
P3(ii)	Pupils use emerging conventional communication. They greet known people and may initiate interactions and activities, for example, dropping objects to prompt interventions from adults. They can remember learned responses over increasing periods of time and may anticipate known events, for example, collecting coats and bags at the end of the school day. They may respond to options and choices with actions or gestures, for example, pointing to or giving one object rather than another. They actively explore objects and events for more extended periods, for example, manipulating objects in piles, groups or stacks. They apply potential solutions systematically to problems, for example, using items of equipment purposefully and appropriately.
P4	Pupils are aware of cause and effects in familiar mathematical activities, *for example, knowing that in a role-play shop a coin can be exchanged for an item; hitting a mathematical shape on a concept keyboard to make it appear on the screen.* Pupils show awareness of changes in shape, position or quantity, *for example, grouping objects that have similar key features such as shape; creating very simple sequences of light or sound using switched equipment; recalling an object which has been placed out of sight*. They anticipate, follow and join in familiar activities when given a contextual clue, *for example, anticipating the next chorus or action in songs and rhymes; matching cakes to plates*.
P5	Pupils sort or match objects or pictures by recognising similarities, *for example, matching shoes or socks by placing next to one placed by an adult; find matching pairs from a collection of pictures; collecting objects given one criterion such as blue or big.* They make sets that have the same small number of objects in each, *for example, distributing sweets into containers so that there are one or two in each*. They solve simple problems practically, *for example, selecting appropriate containers for items of different sizes; checking there is a knife for every fork.*
P6	Pupils sort objects and materials according to a given criteria, *for example, sorting footballs into a net and table tennis balls into a box.* They copy simple patterns or sequences, *for example, copying a drumbeat; copying a simple pattern of repeated movements; copying a pattern of large and small cups*.

P7	Pupils complete a range of classification activities using a given criterion, *for example, sorting a pile of coins by size, colour or shape; sorting all the blue Wellington boots; sorting all the size 6 shoes.* They Identify when an object is different and does not belong to a given familiar category, *for example, removing odd items from sets; collecting items into sorting boxes or drawers*. They respond appropriately to key vocabulary and questions, *for example, 'How many?'*
P8	Pupils talk about, recognise and copy simple repeating patterns and sequences, *for example, recognising and describing simple repeating patterns on textiles or necklaces from different cultures; recognising and describing a pattern of socks on a line; joining in a pattern of hand claps; talking about and copying patterns such as beats in familiar music; shapes made by hand and feet in damp sand; sponge prints.* Pupils use their developing mathematical understanding of counting up to ten to solve simple problems encountered in play, games or other work, *for example, using* *21 tokens or marks to tally events or scoring in games; counting in the school environment; using ordinal words to describe positions and turns*. Pupils make simple estimates, for example, estimating the number of cubes that will fit into a box or the number of strides across a room.

Appendix D: Letter to Western Cape Forum for Intellectual Developmental Disability, Governing bodies and Centre management.

Dear Colleagues

I am enrolled in the Master of Science in Physiotherapy program at the University of Cape Town under the supervision of Professor Jennifer Jelsma. Approval from the Human Research Ethics Committee, Faculty of Health Sciences at the University of Cape Town has been given to protect the rights and safety of persons participating in this study. (HREC REF: 634/2016)

The aim of my study is to examine the correlates of change in educational outcome in children with SPID who are supported by the rural team of the WCED. In addition, the characteristics of the children and validity of the P scales, included in the routine data base, will be examined.

- The objectives of the study are to describe the characteristics and needs of children with SPID in rural educational districts of the Western Cape, supported by the multi-disciplinary outreach team of WCED, in terms of:
    - Demographic and Medical characteristics
    - Functional ability using GMFCS, CFCS & MACS
    - Ability to participate in structured activities using P scales
    - Met and unmet needs for appliances and transport
- To document the nature, content and frequency of intervention by team, where possible. This will include information on parental contact made, by the team and the SCC.

To establish whether the P-Scales is a psychometrically sound outcome measure within this context by determining the:

- Face validity through consultation with a panel of experts who have used the scales
- Reliability as determined by the internal consistency (Cronbach's alpha).
- Responsiveness by determining the effect size of the scores over one year
- Concurrent validity through examining the correlations between the Vineland Adaptive Behaviour Scales II and the scores on the relevant section of the P Scales

To Identify the correlates of change in educational outcome in children with SPID in rural educational districts of the Western Cape, supported by the multi- disciplinary rural outreach team of WCED. Changes in scores will be determined by the following outcome measures:

- Improvement/no improvement on the P scale scores, the primary outcome measure will be the dependent measure

The focus would be on child specific factors influencing change:

- Age
- Probable Health Condition
- General Health (chronic or recurring medical conditions)
- P scale score for Communication (Listening)
- GMFCS
- MACS
- Home Language vs Language of Learning and Teaching
- Nature and frequency of support received from the rural team

The study will be conducted using the routine data available in folders, kept at Riebeeck Valley Special School and using the entire population in the descriptive study. Only about 70-80 participants will have two P scale scores indicated on their individual support plans and incorporated into the correlation study. A research assistant will be employed to enter the data.

To establish concurrent validity of the P scale in the current context, outcomes on the P scales will be compared to outcomes on the Vineland Adaptive Behaviour Scale II. A convenient sample of at least 30 will be used and tested using the above measures. These will be done by members of the rural team. These same children will be used to establish the intra-rater reliability by retesting P scales two weeks apart. This will be done as part of the routine service delivery with no unnecessary disruptions to the logistical procedures of the team.

Routine consent forms are filled in by parents/guardians and will be honoured when using the routine data. I will approach the parent of the child to inform and invite them to participate in the study to establish concurrent validity and intra-rater reliability of the P scales. A separate and different consent form will then be used.

This letter serves to inform you of the study and to make you aware of the potential benefits this study could have for the planning and monitoring of future educational service delivery to children with severe to profound Intellectual Developmental Disability. I need to inform you that the identity of the children, the centre, the educational district and any other role players will be protected at all stages. Only the rural team will have access to the raw data for service delivery purposes.

Please feel free to get in touch with myself or my supervisor or Professor Marc Blockman from the Research and Ethical Committee, Faculty of Health Sciences at the University Of Cape Town should you have any queries or concerns or comments.

1. Karlien Spangenberg

Tel No: 0834550562

Email: karlienspangenberg@gmail.com

2. Supervisor: Professor Jelsma

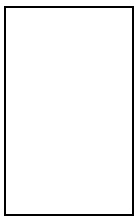
Email: jennifer.jelsma@uct.ac.za

3. Professor Marc Blockman

Chair: The Human Research Ethics Committee, Faculty of Health Sciences at the University Of Cape Town, Old Main Building Groote Schuur Hospital, Floor E52, Room 23, Observatory, 7925.

Appendix E: Questionnaire to establish Face Validity of the P scales:

1. On a scale of one to five, how useful did you find the P scales in assessing educational ability in children with severe to profound Intellectual Developmental Disability in SCCs in the Western Cape?



1=not useful

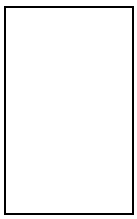
2=hardly useful

3=neutral

4= useful

5=very useful

2. *On a scale of one to five, how many assessments have you done using the P scales?*



1= less than 10

2=Between 11 and 50

3= Between 51 and 100

4= Between 101 and 200

5= More than 200 children

Appendix F: Consent form for routine data collection

I _____, the parent/legal guardian of _____, agree that:

PURPOSE	SIGNATURE	DATE
1. My child can be tested **(Assessment)** by the team from the Western Cape Education Department in order to support my child by means of an individual plan. I understand that this mean the team will read, share and discuss private information in personal and medical files with other professionals.	……	……
3. **Photographs and/or video recordings** can be taken of my child for the use of identification and the personal file of the child. The photos and/or videos can also be used in programs to help in training people to work with your child and other children like him/her. The photos will **NOT** be used for public display on WCED websites or publications. For that, I will sign a different form if the department asks me.	……..	……
Information about my child can be used for **research** to study the needs of people with disabilities and the service they receive in the special care centres. Only the results of tests and assessments that are usually done by the team, on everybody, can be used. I understand the information on the extra page.	……..	……

The team undertakes to treat my child and any information about my child with the utmost integrity and respect.

EXTRA INFORMATION FOR USING INFORMATION FOR RESEARCH

Purpose of the research
The team from the Western Cape Education Department wants to investigate the support services for children in special care centres to decide if they are helpful to your child and other children.

Type of information needed
Information that will be looked at are facts about your child, like: age, gender, language, family structure, social needs and support, diagnoses, tools to help like wheelchairs or hearing aids and level of support needed according to tests. This will mean talking with people that work with your child.

How will information be shared
Facts will be stored in hard copy files as well as on a computer shared by the team from the Western Cape Education Department and members from the University of Cape Town who help the team.

How will participant privacy be protected
Personal information will be kept only in hard copy format, and only the original document will be kept in ring binder files with access restricted to members of the team. The information used for further study will be the information without the child's name and identification.

What are possible risks of storing personal data
Very low to none
Only members of team will have access to personal information. Research results and papers will not include personal information that can identify participants.

Potential Benefits of the research
The information taken from the results of the research will help government departments and other organisations to better plan the support to your child. This will also help other children in your centre and others in South Africa.

The research will also make other people more aware of the needs of children with severe to profound intellectual and physical disabilities in the Western Cape and South Africa. It will also tell other people what work is being done by the government to help.

It can give more students a chance to study this line of work, which will in the end help children with disabilities in our society.

Appendix G: Informed Consent – concurrent validity of P scales

Dear Sir/ Madam

My name is Karlien Spangenberg and I am doing my masters study in physiotherapy at the University of Cape Town. My study involves looking at how we can monitor educational service delivery to children in special care centres by finding appropriate assessment tools. My supervisor is Professor J. Jelsma. To protect the rights and safety of persons participating in this study, approval from the Research and Ethical Committee, Faculty of Health Sciences at the University Of Cape Town has been given.

Please read this letter carefully before making a decision for you to take part in this study or not. If you need help with reading this letter then please ask someone of your choice to help you or alternatively we can provide you with someone to help.

We have come to you as you have a child who is getting help from the Rural Outreach team of the Western Cape Education Department. We use a test called the P scales to see what your child is able to do and what type of support they need. We also use these scales to see whether your child is making progress. Every child on the programme is tested using the P scales and this is not part of the study.

Nothing extra or out of the ordinary is expected of you or your child. Similar to what the Outreach Team usually does, therapists from the team will observe what your child does or does not do during the day. They will ask questions to the care workers at the sthat your child attends to confirm that what they have seen is similar to what the child normally does.

We want your permission to do the following added tests:

The following will be what you give consent to:

1. A psychologist from the Western Cape Education Department will assess your child with a test called the Vineland Adaptive Behaviour Scale II. It means that she will watch what your child does during the day and confirm with the care worker that what she has seen is what the child is doing every day. If a specific action is required from your child, the care worker will be instructed specifically how to bring about that action. This is so that we can compare the results of this test with the P scale results to see if they both tell us the same sort of information about your child.

2. An occupational, speech and physiotherapist will assess your child with tests called the P scales for Language, Mathematics and Physical Education as usual. This means that they will look at how your child takes part in structured activities during the day. If participation in a specific activity is required from your child, the care worker will be requested to include and instruct specifically how to structure that activity. The same tests will be repeated two weeks after the first tests were done to check that the results are the same.

3. The tests will take place in the Special care centre that your child attends within the hours that the centre is open. Where possible, the child will be observed in his/her natural environment of the classroom or playground between other children and in the presence of their care workers. Only in exceptional cases will a child be withdrawn from the group along with his/her care worker for the duration of the test.

Great care will be taken to ensure that no harm will be done during this process.

Please note that for your child to take part in the study and undergo the extra tests or not will be up to you. No payments will be made to you because your child's information is used. You will not be forced to take part in the study. If you decide at any time to withdraw from the study then it will not prevent your child from getting further support from the SPID team.

All information gathered on your child will be kept confidential. Your child's names and personal details will not be revealed in the study and any articles that might be published in the future. We hope that this is clear, but if there are any further questions or problems that should come up, please feel free to get in touch with myself or my supervisor or Professor Marc Blockman from the Human Research Ethics Committee, Faculty of Health Sciences at the University of Cape Town.

Contact details

1. Karlien Spangenberg

Tel no: 0834550562

Email: karlienspangenberg@gmail.com

2. Supervisor Email: Jennifer.jelsma@uct.ac.za

2. Professor Marc Blockman

Chair: The Research and Ethical Committee, Faculty of Health Sciences at the University Of Cape Town, Old Main Building Groote Schuur Hospital, Floor E52, Room 23, Observatory, 7925.

Statement of consent

I ……..have read (or was read to me by …….) the information letter . I understand the content of the information letter and what will be done as part of the research study. An opportunity was given to me to ask questions and my questions were answered. I understand that my child's participation in the research study is completely voluntary and of my own free will and that I can withdraw at any time without affecting my child of me in any way.

Signed: ..... Date .....

Appendix H: Informed Assent

(Read by parent, direct support person or centre manager with the use of gestures and or alternative communication methods – see instruction leaflet)

Dear ..... (name of child or adolescent)

Please look and listen. Is it ok if this teacher/aunt works with you?

This teacher's name is Karlien. She wants to hear and see what you can do. Teacher Karlien and her other teacher friends will talk to mommy. The aunties will talk to mommy or to me. You can show us and we will watch what you can do. If you need help, I will help you. The teachers will show me how to help you. Is this ok?

Then the teachers will write what you can do. The teachers will also ask your friends to look at them. The teachers will write down what they hear and see about you and your friends. Then we all know better what you need. Then the teachers will show us how to play. The teacher will show mommy and me how to help you so that you can do things by yourself.

If this is ok, please say yes. Or you can nod up and down, show thumbs up, use your communication board or device to indicate yes, or smile.

If this is not ok, please say no. Shake your head, show thumbs down, use your communication board or device or turn away from me.

If you are uncertain, turn to your mommy or to me. Ask them to say and show again.

Contact details

1. Karlien Spangenberg

Tel: 083 455 0562

karlienspangenberg@gmail.com

2. Supervisor: Professor Jennifer Jelsma

Email: jennifer.jelsma@uct.ac.za

3. Chair of the Research and Ethical Committee, Faculty of Health Sciences at the University Of Cape Town: Professor Marc Blockman.

Tel: 0027(21) 406-6492

Information leaflet: Informed Assent

Dear parent/ direct care worker

Please ask the child/teenager if it is ok if the therapists from the education support team looks at what he/she does. Please use the words of the letter above, but do it in the manner that you know the child will understand. Use demonstration or assistive devices if necessary.

If the child is not able to show that he can choose between things or if the child is not really very aware of what is happening around him, it is not necessary to ask the child/teenager to indicate yes or no. Simply tell the child/teenager exactly what will be done with him just before it is done. Then please look for any sign that the child/teenager is uncomfortable or in distress. As a witness, if the child was not uncomfortable or in distress during the session, please sign the form below.

Statement of Assent

The letter was read and/or demonstrated to me,……..(name of child). I understand what will happen. I understand that I can say no. I had a chance to show yes or no. If I did not know, they said and showed again.

Sign used to indicate yes:

……. ……..

Date and place

……. ……..

Researcher Date and place

……. ……..

Witness Date and place

As the direct care worker, who knows .....(name of child) I ..... declare that the child/teenager was not in distress or showed signs of discomfort while the support team from education looked at his/her abilities to respond and engage during daily activities that happen at the centre on a regular basis.

……. ……..

Researcher Date and place

…… ……

Care Worker Date and place

……. ……..

Witness Date and place

Appendix I: Article published in the African Journal of Disability – The validation of an educational database for children with profound intellectual disabilities

African Journal of Disability

ISSN: (Online) 2226-7220, (Print) 2223-9170

The validation of an educational database for children with profound intellectual disabilities

Authors:

Karlien Spangenberg[1]

Lieselotte Corten[2]

Winnie van Rensburg[1]

Elizma Kilian[1]

Judith McKenzie[2]

Hein Vorster[1]

Jennifer Jelsma[2]

Affiliations:

[1]Children with Severe and Profound Intellectual Disabilities Inclusive Education Outreach Team, Western Cape Department of Education, South Africa

[2]Department of Health and Rehabilitation Sciences, University of Cape Town, South Africa

Corresponding author:
Karlien Spangenberg, karlienspangenberg@gmail.com

Dates:

Received: 27 Oct. 2015

Accepted: 13 July 2016

Published: 23 Sept. 2016

How to cite this article:
Spangenberg, K., Corten, L., van Rensburg, W., Kilian, E., McKenzie, J., Vorster, H., *et al*., 2016, 'The validation of an educational database for children with profound intellectual disabilities', *African Journal of Disability* 5(1), a237.

http://dx.doi.org/10.4102/ajod.v5i1.237

Background: The Western Cape Forum for Intellectual Disability took the South African Government to court in 2010 on its failure to implement the right to education for Children with Severe and Profound Intellectual Disability. Subsequently, multidisciplinary teams were appointed by the Western Cape Education Department to deliver services to the Special Care Centres (SCCs). Initially, minimal information was available on this population.

Objectives: The purpose is to document the process of developing and validating a database for the collection of routine data.

Method: A descriptive analytical study design was used. A sample of convenience was drawn from individuals under the age of 18 years, enrolled in SCCs in the Western Cape. The team who entered and analysed the data reached consensus regarding the utility and feasibility of each item.

Results: Data were collected on 134 children. The omission of certain items from the database was identified. Some information was not reliable or readily available. Of the instruments identified to assess function, the classification systems were found to be reliable and useful, as were the performance scales. The WeeFIM, on the other hand, was lengthy and expensive, and was therefore discarded.

Discussion and conclusions: A list of items to be included was identified. Apart from an individual profile, it can be useful for service planning and monitoring, if incorporated into the central information system used to monitor the performance of all children. Without such inclusion, this most vulnerable population, despite court ruling, will not have their right to education adequately addressed.

Introduction

The second United Nations (UN) Millennium Development Goals included the achievement of universal primary education (UN) by 2015, which encompasses children with disabilities. Yet for millions of children with physical and intellectual disability this goal may not be close to realisation, despite various UN Declarations affirming their rights to education. Children with more severe and profound disabilities have been especially disadvantaged.

Within the Western Cape (WC), there are estimated to be approximately 3000 children with severe or profound intellectual disability (CSPID) (Kleintjies *et al*. 2006; McKenzie, McConkey & Adnams 2013a). In this study, Kleintjies *et al*. defines profound intellectual disability as having IQ levels below 30. The DSM-5 (American Psychiatric Association 2013) stipulates the following specifiers in terms of the severity of intellectual disability:

The various levels of severity are defined on the basis of adaptive functioning, and not IQ scores, because it is adaptive functioning that determines the level of supports required. Moreover, IQ measures are less valid in the lower end of the IQ range.

Therefore, this population of children has both intellectual and adaptive functioning deficits in the domains of conceptual, social and practical domains. In the practical domain (American Psychiatric Association 2013), it means that:

> The individual requires support for all activities of daily living, including meals, dressing, bathing, and elimination. The individual requires supervision at all times. The individual cannot make responsible decisions regarding well-being of self or others.

The prevalence of sensory impairments, visual and hearing, in people with intellectual disabilities is 10 and 40–100 times greater than in the general population (Carvill 2001). Prior to the court action described below, there was little recognition that these children had the right to educational services provided by the National Department of Basic Education, a situation similar to most African countries (McKenzie, McConkey & Adnams 2013b).

The Western Cape Forum for Intellectual Disability, on behalf of its members, took the South African Government to court on the matter of the rights of CSPID in the WC in 2007 (South African Legal Information Institute 2007). The application was successful, and the judgement required the Western Cape Education Department (WCED) to take incremental steps to ensure that such children have affordable access to a basic education of an adequate quality and to report back on the progress made in implementing the judgement. Implementation entailed supporting organisations and centres that provide education and care to CSPID.[11] As a consequence, four multidisciplinary educational teams were appointed to work with CSPID in special care centres (SCCs) in the WC. Each team consists of a psychologist, a learning support educator, an occupational therapist, a physiotherapist, and a speech and language therapist. The teams supported approximately 35 SCCs in six of the eight education districts in the WC by March 2013.[12] This amounts to about 1050 children and about 120 care staff at the SCCs.

The four CSPID teams have adopted a phased approach to the roll out of educational inclusion in the SCCs, beginning with relationship building with the centre staff, identifying the children, consulting with parents, formalising the content and scope for programme development and teaching care staff to provide educational stimulation to the children. Goals are set and prioritised for each child. Centre caregiver training is done on site, and this is practical and interactive in nature. The various team members are consulted by a representative involved in developing a national curriculum for profound intellectual disability (PID), which links with the National Curriculum Framework for children birth to four years and the curriculum for severe intellectual disability, under development.

At the commencement of the programme, there was very little information available with regard to the demographics, educational accomplishments or functional limitations of the children enrolled in the programme. As a result, there was no baseline information from which to map the progress of the children and little evidence to monitor the efficacy of the programmes. Literature review on similar projects around the globe did not render satisfactory results. Apparent inconsistencies in the definitions of disability hamper international comparison (Robson & Evans 2003), especially true in special education, in which different systems lead to even more controversy (Robson & Evans 2003).

Every typically developing child has their educational progress monitored by the national Department of

[11] .This process is described in a paper by McKenzie J, Pillay N, Duvenhage CM, Du Plessis E and Jelsma J: 'Implementation of educational provision for children with severe and profound intellectual disability in the Western Cape: From rights to reality which is in preparation'.

[12] .Report on Activities of the Provincial Teams for Children with Severe to Profound Intellectual Disabilities (CSPID), for the period April 2012 to March 2013, submitted to the WCED.

Education, through the Central Education Management Information System (CEMIS). There was thus a need to develop a database appropriate for the needs of CSPID. This database should form part of systems for assessing and monitoring changes in children's physical, social, communication and cognitive competences as well as their health, personal care and emotional well-being. Children attending these SCCs are only the tip of the iceberg of CSPID, as many children are still excluded from any form of education. However, due to the brief and logistical constraints of the multifunctional teams, this study could not include these children.

Aim of the study

The purpose of this paper is to document the process of developing and validating a database for the collection of routine data for CSPID. This could potentially form part of CEMIS and be administered centrally. It is hoped that the documentation of this process will assist other organisations wishing to develop similar databases.

Research method and design

An iterative process, including group discussions, training sessions and online discussion, was utilised to reach consensus on suitable items for the database. A descriptive analytical study design was used to pilot the prototype database.

Participants

The participants included eight to ten members. To objectify the development of the database, the representatives of the four CSPID teams were joined by representatives from within the Department of Health and Rehabilitation Sciences of the University of Cape Town. The participants represented the disciplines of psychology, teaching, occupational therapy, speech and language therapy, and physiotherapy. Information gained through the initial audit of the SCCs and the subsequent findings of the original team were considered in this process.[1] The data collection form was rolled out to 12 centres in 3 of the rural districts by September 2014 to assess all children in these centres, as part of their routine management. The sample for the validation study was drawn from all individuals under the age of 18 years, who were enrolled in 10 of the 12 centres serviced by the rural team, as indicated on registers for September 2014. The exclusion of two of these centres was due to logistical constraints in service delivery at that time. As the purpose was to explore the feasibility and usefulness of the data collection form, the sample was one of convenience and not necessarily representative of all 273 individuals serviced by the rural team by September 2014. The results were then presented to the members of the small task team who reached consensus with regard to which items should be included in the definitive database.

Instrumentation

The database items were identified through a series of consensus meetings. The multidisciplinary nature of the team contributed to the face validity of the instrument. There was considerable discussion as to which demographic and health condition items should be included, as well as items relating to medical management, provision of assistive devices and therapeutic interventions.

All members were requested to identify standardised instruments that were valid and responsive for the measurement of the different aspects of functioning of each child. The criteria for inclusion were that the instrument should be able to be used by any member of the team, that it should be robust and that it would monitor important functional and educational skills in the target population. The standardised instruments considered included, amongst others, the Gross Motor Function Measure (McDowell 2008), the Alberta Infant Motor Scale (Piper *et al*. 1992), the Bayley Scales of Infant Development (Milne, McDonald,

Comino 2012), the Vineland Social Emotional Early Childhood Scale (Van Duijn *et al*. 2009) and the Receptive One Word Vocab Test (Tafiadis *et al*. 2010). However, it was agreed that each of these tests required specialised, discipline specific skills to be used routinely by any member of the team.

The instruments that were ultimately chosen included different classification systems: the Gross Motor Function Classification System (GMFCS) (McDowell 2008), the Manual Ability Classification System (MACS) (Eliasson *et al*. 2006) and the Communication Function Classification System (CFCS) (Hidecker *et al*. 2011). These were included to give a gross measurement of the level of functioning of the children and a summary can be found in Tables 1–3.

In addition, the WeeFIM (Ottenbacher *et al*. 2000), which gathers data on self-care, mobility and cognition, was included to monitor the independent functioning of the children.

The performance scales (P-scales), which are the national curriculum performance attainment targets for children with special education needs in the UK, were also included (Department for Education 2014). The attainment scales are differentiated performance criteria and give an idea of the child's level of participation to structured activities throughout the day, hence measuring educational-oriented achievement. The P-scales use eight performance levels to illustrate learning. Levels P1 to P3 show the earliest levels of general attainment. Levels P4 to P8 show subject-related attainment, focusing on extending understanding and connecting knowledge. The extracts from the P-Scale level descriptions 2009 in Table 4 will assist in understanding the value and relevance of this tool (Qualifications and Curriculum Authority 2009).

In addition, the existing data collection forms, which included information related to demographic, medical and need for

TABLE 1: Gross motor function classification system.

Level	General heading description
Level I	Walks without limitations
Level II	Walks with limitations
Level III	Walks using a hand-held mobility device
Level IV	Self mobility with limitations; may use powered wheelchair
Level V	Transported in a manual wheelchair

Source: GMFCS – E & R © Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingstone 2007 *CanChild* Centre for Childhood Disability Research, McMaster University

TABLE 2: Manual ability function classification system.

Level	Description
Level I	Handles objects easily and successfully
Level II	Handles most objects but with somewhat reduced quality and/or speed of achievement
Level III	Handles objects with difficulty; needs help to prepare and/or modify activities
Level IV	Handles a limited selection of easily managed objects in adapted situations
Level V	Does not handle objects and has severely limited ability to perform even simple actions

Source: Eliasson AC, Krumlinde Sundholm L, Rösblad B, Beckung E, Arner M, Öhrvall AM. The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. Developmental Medicine and Child Neurology 2006 48:549–554

TABLE 3: Communication function classification system.

Level	Description
Level I	Effective sender and receiver with unfamiliar and familiar partners
Level II	Effective but slower paced sender and/or receiver with unfamiliar and/or familiar partners
Level III	Effective sender and receiver with familiar partners
Level IV	Inconsistent sender and/or receiver with familiar partners
Level V	Seldom effective sender and receiver even with familiar partners

Source: Hidecker, M.J.C., Paneth, N., Rosenbaum, P.L., Kent, R.D., Lillie, J. *et al.* 2011 Developing and validating the Communication Function Classification System (CFCS) for individuals with cerebral palsy, Developmental Medicine and Child Neurology. 53(8), 704–710

TABLE 4: Extracts from P-Scale level descriptors – English.

Level	Language
P1(i)	Pupils encounter activities and experiences. They may show simple reflex responses, *for example, startling at sudden noises or movements.* Any participation is fully prompted'.
P1(ii)	Pupils show emerging awareness of activities and experiences. They may have periods when they appear alert and ready to focus their attention, *for example, attending briefly to interactions with a familiar person.* They may give intermittent reactions.
P2(i)	Pupils begin to respond consistently to familiar people, events and objects. They react to new activities. They begin to show interest in people, events and objects, *for example, smiling at familiar people.* They accept and engage in coactive exploration.
P2(ii)	Pupils begin to be proactive in their interactions. They communicate consistent preferences and affective responses, *for example, reaching out to a favourite person.* They recognize familiar people, events and objects. They perform actions, often by trial and improvement, and they remember learned responses over short periods of time. They cooperate with shared exploration and supported participation.
P3(i)	Pupils begin to communicate intentionally. They seek attention through eye contact, gesture or action. They request events or activities, *for example, pointing to key objects or people.* They participate in shared activities with less support. They sustain concentration for short periods. They explore materials in increasingly complex ways. They observe the results of their own actions with interest. They remember learned responses over more extended periods.
P3(ii)	Pupils use emerging conventional communication. They greet known people and may initiate interactions and activities. They can remember learned responses over increasing periods of time and may anticipate known events. They may respond to options and choices with actions or gestures. They actively explore objects and events for more extended periods. They apply potential solutions systematically to problems.
P4 speaking	Pupils repeat, copy and imitate between 10 and 50 single words, signs or phrases or use a repertoire of objects of reference or symbols. They use single words, signs and symbols for familiar objects and to communicate about events and feelings.
P4 listening	Pupils demonstrate an understanding of at least 50 words, including the names of familiar objects. Pupils respond appropriately to simple requests which contain one keyword, sign or symbol in familiar situations, for example, 'Get your coat', 'Stand up' or 'Clap your hands'.

and availability of assistive devices, were expanded to include additional information.

It is to be noted that the functional items are to be reassessed at regular intervals to monitor change in status. However, the repeated measurements were not tested as part of this pilot.

Procedure

The process was started in November 2013 with the support of the WCED. Collaboration between members of the CSPID team and the University of Cape Town was initiated. Permission was obtained from the Human Research Ethics Committee of the University of Cape Town (HREC REF: 109/2016). The entire group met and agreed in principle that a database should be developed. Approximately eight meetings were held in the course of the next 12 months including two training sessions on the use of the WeeFIM and the P-scales. A smaller task team was then established to continue this work. An initial list of items was circulated to the larger group, and based on the responses a prototype database was developed and registered with the HREC of the University of Cape Town. The prototype was subjected to a feasibility study with 20 participants. Based on these results, further amendments were made, including the use of drop-down boxes to ensure standardisation of responses under each item.

Source: Level descriptors P1 to P8 © Qualifications and Curriculum Authority 2009 Great Britain

All participating children had been admitted to the programme prior to the introduction of the database. They had an existing questionnaire, filled in for each child at the specific centre, with relevant data. Additional information was then added to their records. Based on information previously gathered at admission, as well as after the administration of the standardised instruments, a research assistant then collected all this data from

the CSPID files, using a survey instrument application, Magpi (http://home. magpi.com/).

Since the inception of the database, consent for including the information of the children enrolled in the CSPID programme and for auditing of procedures has been added to the admission forms. Informed consent was obtained from the parents of all enrolled children. Confidentiality was ensured by removing the names of the children and their centres from the data set prior to analysis.

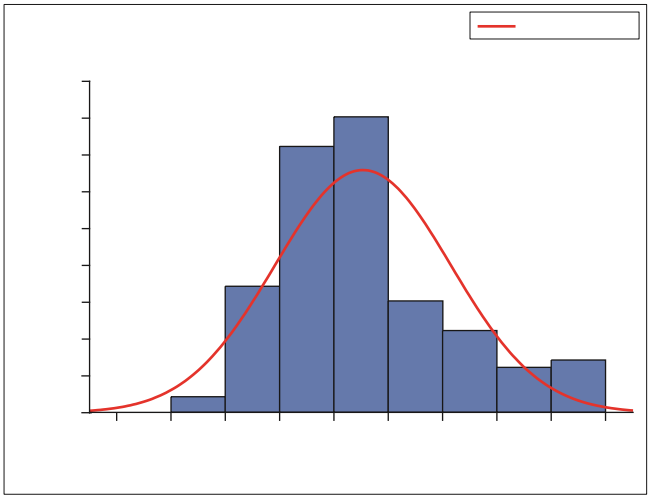
Data analysis

Descriptive statistics were used throughout. The three therapists who had utilised the database discussed the statistical outcomes and the value of the information gained from each item until consensus was reached as to the utility and feasibility of each of these headings.

Results

Of the 134 children recruited, 58% were male. Three quarters of the children spoke Afrikaans, and with three exceptions the others spoke isiXhosa.

Names, surnames and date of birth were 100% available at the time of the study and only one centre did not record home addresses. The mean age was 9.1 years (Standard deviation [SD] = 3.2 years, range 2.7–17.6 years; see Figure 1). Table 5 shows the categories, in terms of grants received, found in the folders. The receipt of grants was unrecorded in 96 of the cases. Other items, such as hospital folder numbers, parental income or socio-economic status were not found to be widely available.



Source: Sample drawn from database of children supported by the rural team for children with severe to PID (WCED) September 2014

FIGURE 1: Histogram of the ages of the children (N = 134).

TABLE 5: Results on item – grants.

Type of grant	No. of children
Child support	11
Disability	17
Foster	10
Unknown	96

Source: Sample drawn from database of children supported by the rural team for children with severe to PID (WCED) September 2014

Data on meeting the need in terms of transport were easily accessible. All children had access to transport arranged or supplied by the SCC.

Where the diagnosis was available, it was entered into the database as written in the folder with cerebral palsy (CP), idiopathic intellectual disability and epilepsy being the most common. It was necessary to recode certain diagnoses (Table 6) for the sake of standardisation; for example, hemiplegia, spastic CP and athetoid were recoded as CP. The results of the items related to the availability of appliances are given in Table 7. Only three children were identified as being in need of an appliance.

TABLE 6: Results on item – health conditions.

Variable	Count	Children (%)	Conditions (%)
Cerebral palsy	58	43.3	24.3
Intellectual disability	33	24.6	13.8
Epilepsy	26	19.4	10.9
Chromosomal	16	11.9	6.7
Autism spectrum disorder	13	9.7	5.4
Visual impairment	11	8.2	4.6
Foetal alcohol syndrome	10	7.5	4.2
Microcephaly	10	7.5	4.2
Hydrocephalus	8	6	3.3
Hearing impairment	7	5.2	2.9
Meningitis	6	4.5	2.5
Attention deficit hyperactivity disorder	5	3.7	2.1
Speech impairment	5	3.7	2.1
Muscular-skeletal impairment	5	3.7	2.1
Global developmental delay	4	3	1.7
Kidney/liver disorder	4	3	1.7
Congenital neurological abnormality	3	2.2	1.3
Behaviour disorder	2	1.5	0.8
Spina bifida	2	1.5	0.8
Allergic rhinitis	2	1.5	0.8
Other	6	4.5	2.5
Unknown	3	2.2	1.3
Total	239	-	100

Source: with severe to PID (WCED) en supported b
September 2014 N = 134 children, 239
health conditions.

TABLE 7: Results on item – availability of iances.
appl

Variable	Buggy	Wheelchair	Splint	Standing frame	Hearing aid	Spectacles
No	90	124	127	134	134	132
Yes	39	7	6	0	0	2
Unknown	4	2	6	0	0	0
Need one†	1	1	1	†	†	†

Source: Sample drawn from database of children supported by the rural team for children with severe to PID (WCED) September 2014

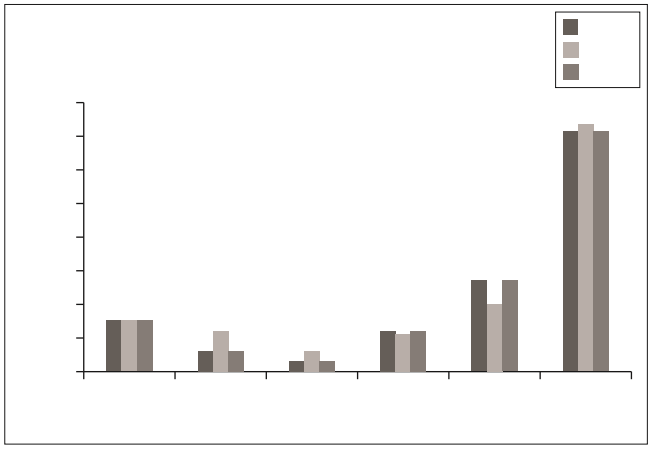
†, The need for visual and hearing aids was not tested.

The classification systems were applied only to those children who had been diagnosed with CP (Figure 2), a sample of 63. Peaks were observed at mild levels (Levels I and II) and unable to do (Level V) for the MACS and GMFCS. In contrast, a steadily increasing percentage of children had problems with communication, with two thirds falling in the most severe category. Similar peaks were observed with the scores on the P-scales, with peaks at p1.ii and p4 and p5 (Figure 3, presentation of P-scale scores of 122 children)

The WeeFIM was administered to 27 children, with the results of the self-care domain recorded in Table 8, as an example of the results obtained. Because of the administrative burden, a small sample of convenience was used.

Due to logistical constraints, not all of the 134 children were tested using all of the instruments, resulting in the missing data reported in Figures 2 and 3.

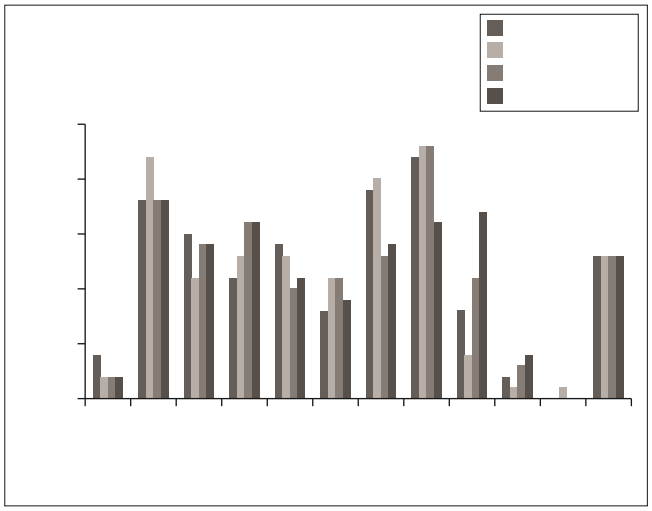
The three therapists involved discussed the feasibility of each item and reached consensus regarding the utility, feasibility and possibility of standardisation thereof, to ensure future



Source: Sample drawn from database of children supported by the rural team for children with severe to PID (WCED) September 2014

MACS, manual ability classification system; GMFCS, gross motor function classification system; CFCS, communication function classification system.

FIGURE 2: Number of children (y-axis) scoring at the different MACS, GMFCS AND CFCS levels (x-axis).



Source: Sample drawn from database of children supported by the rural team for children with severe to PID (WCED) September 2014

FIGURE 3: Frequency (y-axis) of P-scale scores (x-axis) across all subject areas.

reliability. Based on the results of the pilot testing, several items were altered. Items deemed not to meet the criteria of these three constructs were deleted or amended. Their conclusions and suggested amendments are listed below.

The child's home language was indicated in the centre folder. Apart from Afrikaans and Xhosa as preferred language, the minor exceptions were French, Tsonga or Sotho.

The use of the national identification (ID) number rather than a yet-to-be-allocated CEMIS number is preferred. A unique number is necessary to ensure confidentiality, and it had been thought that a CEMIS number would be the most appropriate. Identity documentation is available in the majority of centres and accompanied by birth certificates, in most cases. Initially, it was thought that hospital numbers could assist with health-related queries. It became apparent that ID numbers would best serve as the reference number in the attempt to align databases from different government departments as well. ID numbers should be utilised as the

TABLE 8: WeeFIM – self-care domain.

Assistance	Bowel management	Bladder management	Toileting	Dressing lower body	Dressing upper body	Grooming	Eating
1 Total	16	16	17	16	16	13	11
2 Maximal	1	1	2	7	7	8	2
3 Moderate	1	1	-	-	-	-	2
4 Minimal	1	1	-	1	1	-	1
5 Supervision	-	-	3	2	2	5	6
6 Modified independence	1	1	-	-	-	1	-
7 Complete independence	7	7	5	1	1	-	5
Total	**27**	**27**	**27**	**27**	**27**	**27**	**27**

Source: Sample drawn from database of children supported by the rural team for children with severe to PID (WCED) September 2014

unique identifying number, which could also be used for children not attending SCCs.

Information with regard to the age of children is extremely important and was available for all. The results identified the need for early intervention and raises questions as to why there was a sudden drop in attendance after the age of 10 years. Another useful finding was that there are several older children who are still attending the centres. Age-related information will be useful both in terms of practical planning of age-appropriate programmes and interventions, as well as for monitoring and planning of future service delivery.

It was agreed that the collection of socio-economic data was difficult to source and unreliable. It was decided to replace employment status with family structure. Similarly, Hospital Payment Scale, which did not render the desired information, was replaced with income category. The Screening Identification Assessment and Support (SIAS) document (Department of Basic Education 2014) acknowledges the essential role of parents in the education and the development of an individual support plan for their child. After data collection, it became apparent that the term disability grant was used incorrectly, as it applies to adults. It was decided to specify the options as follow: *child support*, *care dependency*, *foster care* or *combined foster* and *care dependency grants*. Although there were many missing entries, the team agreed that this was important information which should be gathered in future, as this indicates whether a child receives the appropriate support from the state or not. Should the latter be found, the parent can be guided to the relevant authorities.

The health conditions were available in the folders, but the coding was unstandardised. Intellectual disability was only indicated on a number of folders, mainly those with no other condition. These children with no other diagnosis indicated in their folders are represented in Table 3 as intellectual disability. The team therefore suggested that the International Classification of Disease (World Health Organization 2008) codes be utilised for the primary diagnosis. This diagnosis informs the medical, nursing and therapeutic interventions that might be required. In some cases, there was no clear diagnosis recorded, and the team suggested that there be a second health condition code titled 'Probable health condition'

which would be based on the clinical symptoms and the judgement of the team members. It is suggested that the third health condition code be related to the aetiology of the condition and that the Global Burden of Disease categories should be utilised. It was agreed that although it might be difficult to gather accurate information, it was important to include the health condition as to inform prevention of conditions, progression of the conditions and management. The coding of the medication was also problematic (although not reported on above) as in some cases, it was coded under generic names, others under brand names and sometimes in terms of the indication for the medication. The final suggestion was that besides coding the name of the medication, the type of medication should be indicated. It was agreed that information relating to chronic medication should be gathered, as it would give an indication of the need for possible nursing support to the SCCs.

With regard to appliances, there was inconsistency between the number of children reported to have spectacles and hearing aids and the number of children reported to have visual or hearing impairments. This highlighted the need for screening of sensory impairments before judging the need of these assistive devices. The absence of an item related to Alternative, Augmented Communication was also noted, and this was added to the list of assistive devices.

The intervention that the child receives from sources other than CSPID should be entered under the headings medical, therapeutic and other stimulation activities, instead of simply medical intervention.

The classification systems, as standardised measures of gross motor, manual and communication ability, has a low administrative burden, is robust and can be used across disciplines. The functional abilities of the children have implications on how they can participate in stimulation activities. Activities need to be adjusted, to accommodate for these functional limitations. The classification systems, thus aid in the easy identification of the children in need of therapeutic intervention to optimise their participation to classroom activities.

Rather than using all the P-Scales, it was suggested that the most useful 'subject areas' be identified, renamed and implemented. 'English' were substituted with *Language – Speaking and Listening* – to cover all other official Languages used in the SCCs. The home language of the child will thus be targeted, and not one specific, preselected Language. 'Using and Applying Mathematics' was chosen. These two represented priority areas and *Physical Education* was added to represent an additional skill, according to subject areas outlined in the UK guidelines (Qualifications and Curriculum Authority 2001). These three were chosen, as they correlate to the domains of motor development, cognitive development as well as communication and language development. These were the areas stipulated in the Draft Framework for Therapeutic and Stimulation Programme: Children with Severe to Profound Intellectual Disability (CSPID) developed by the Provincial CSPID team of WCED in November 2012.[13] Personal and Social Health Education (PSHE) and Citizenship (P-Scales), representing social-emotional skills, formed part of the initial subject areas under investigation, but due to logistical reasons, not implemented to the same extent, and thus not incorporated into the data set. For feasibility of execution in the field, it was unrealistic to incorporate more subject areas. These items appeared to be sufficient to plan basic educational activities and monitor progress at this stage.

The WeeFIM was found to be too time consuming for routine collection and excluded from the final database, although it could be useful at an individual level.

[13] .Draft Framework for Therapeutic and Stimulation Programme: Children with severe to profound intellectual disability, developed by Provincial CSPID team November 2012, submitted to WCED.

The final version of the database is presented in the Appendix 1.

Discussion

This paper has documented the development and pilot testing of a database of routinely collected data for CSPID and explored the utility of this data. Based on the results of the pilot testing, several items in the prototype database were altered. There were several lessons learned from the pilot and, as most of the information was relatively easy to access, the therapists expressed confidence in the results. However, where items, such as hospital folder numbers, parental income or socio-economic status, were not found to be available, the utility of having such an item was questioned. It was brought to the attention of the authors that access to data of the Western Cape Department of Health can be gained by the use of identity numbers or name and surname with date of birth. Referrals are made to local clinics or districtbased rehabilitation services. Hospital numbers are thus not essential and in effect redundant.

During the course of data collection, it came to the attention that a rare few children had access to private medical care. This elicited a debate about whether it can be assumed that all children in this population had similar socio-economic circumstances or whether this should form part of routine data collection. The learner profile as described in the SIAS document (Department of Basic Education 2014) only includes information on family structure and type of social grant. It is therefore suggested to suffice with these two items, in line with SIAS documentation, as part of routine data collection for CSPID at this stage.

Higgs, NT (Higgs 2007) states that 'self-reported income data in South Africa is notoriously unreliable'. The inclusion of income category should therefore be reconsidered. In the Support Needs Assessment part of the SIAS document (Department of Basic Education 2014) the following other factors are mentioned as possible barriers to learning, namely: number of schools attended, refugee/immigrant status, substance abuse, domestic violence, divorce, neglect, disabled or ill parents and poverty stricken background. Models, like the American Association on Intellectual and Development Disabilities conceptual framework for human functioning (Buntinx & Schalock 2010), propose an outline to integrate activities from different disciplines involved in service delivery to people with intellectual disability. Context forms a crucial part of measuring Human Functioning, as proposed by Buntinx and Schalock. It is advised by the authors that role players draw from items suggested by Higgs (2007) and Berry *et al*. (2013). Part three of South African Child Gauge 2013 also outlines vital pointers on the socio-economic rights of children, which are a subset selected from the website www.childrencount.ci.org.za. As the above mentioned factors have a high prevalence in people with intellectual disabilities (Adnams 2010), future inclusion of these items might have to be considered by the relevant authorities.

For other items, such as health condition and medication, the information was generally available although challenges remain. By default, all of the children admitted to a SCC are because of intellectual disability and it should therefore be excluded from the list of conditions. It was also considered necessary to provide more details regarding the interventions that the children received.

It became clear on analysis that such a database will collect much useful information that can inform the nature, content and extent of service delivery to CSPID and monitor the impact of such service. For instance, the pilot revealed that there were very few children under the age of 4 years attending the centres. The percentage reflected in this study is lower than the 25% of CDG beneficiaries between 0–6 years of age, found to be attending early learning facilities in the local community (Department of Social Development, DWCPD & UNICEF 2012). This raises the question as to whether young CSPID are receiving

early intervention, and if so, to what extent and of what nature? It is beyond the scope of this paper to really contemplate the reason for the sudden drop in numbers at the age of 10. However, appropriate school placement (Department of Social Development *et al*. 2012) and severe behavioural challenges (Carvill 2001) come to mind, but there will surely be other factors to consider. The number of older children who will be leaving the centres speaks to the need to have appropriate care centres for young adults, as well as improving the education of both younger children and adolescents. As so many children presented with health conditions, which would influence physical functioning and/or require medication, it is clear that a

multidisciplinary team, including educationalists and allied health professionals such as therapists, is essential. The small numbers of children still in need of physical assistive devices indicates that delivery of appliances, such as wheelchairs and buggies, has been appropriate and successful. On the other hand, very few children with sensory impairments received aids such as spectacles, hearing aids and communication devices. This highlights the need for adequate screening of sensory impairments. Given the high prevalence of sensory impairments (Department of Social Development *et al*. 2012) and the resultant impact on learning, this should be prioritised.

The language used by staff members in the centres did not get reflected in the original data set. The language of learning and teaching is important in terms of planning service delivery. The data on home language might appear to be in contrast to the figures for the whole of the WC, but is the reality for the rural parts of the province, which were included in the study. Only one of the centres used Xhosa as the language of instruction, one centre used both Afrikaans and English and the others instructed mainly in Afrikaans. As the focus of the team is on communication and not teaching a specific language, using the home language of the child is encouraged as far as possible.

Availability of transport is of utmost importance. Most children cannot afford personal or public transport, which would result in non-attendance or a high degree of absenteeism. Unfortunately, this database underestimates the need for transport as it does not reflect the number of children not gaining access to the SCC because they reside outside the area covered by centre transport. The need in terms of transport, in reality, is thus bigger than reflected in these statistics.

For many children the reason for not attending a SCC is probably or partly due to inaccessibility of transport. The need is to expand the use of the data set for children on a waiting list at that particular centre. In doing so, it will be a start to account for children whose rights have not been met. It is beyond the logistical constraints of the multifunctional teams to venture further out into the community. In the metro areas, a non-profitable organisation (NPO) is employed by the Department of Social Development to develop home programs for children with no access to SCC's or schools. In the rural areas, due to the vast distances involved, the authors are of the opinion that if would be more feasible to strengthen the means of the rural CSPID team, with the brief to support out of centre children as well.

The need for therapeutic expertise, across the disciplines, is indicated by the large numbers of children with CP, classified at the most severe levels of the MACS, GMFCS and the CFCS. Although initially developed specifically for use in CP (Bodkin, Robinson & Perales 2003), there is a need to utilise these systems with children with other diagnoses apart from CP. Although the items appear to be sufficiently generic to apply to children with other diagnoses, the validity of this

use will need to be established. The Gross Motor Function Classification System (GMFCS), although robust and suitable to describe how severe the child with CP is affected, it was not developed with the purpose of measuring difference over time or subsequent to intervention (Adams 2009). The same

is true for the other classification systems. Each discipline will thus have to further investigate appropriate outcome measures within their respective scope of service delivery. This is a fragmentary approach, probable only possible to administer on a carefully selected few. Although the Vineland Screener 0-12 years research version (Van Duijn *et al*. 2009) was discarded as a measurement for routine use, it is suggested that Vineland Adaptive Behavior Scales (2nd ed.) (Sparrow, Cicchetti & Balla 2005) be reconsidered. It is standardised and has a more holistic approach which includes most of the domains applicable to CSPID.

The Vineland Adaptive Behavior Scales (2nd ed.) (Sparrow, Cicchetti & Balla 2005) assesses adaptive behaviour, which determines severity and consequently the level of support required (American Psychiatric Association 2013). The DSM5 defines the conceptual domain for PID as the following:

> Conceptual skills generally involve the physical world rather than symbolic processes. The individual may use objects in goaldirected fashion for self-care, work, and recreation. Certain visuospatial skills, such as matching and sorting based on physical characteristics, may be acquired. However, co-occurring motor and sensory impairments may prevent functional use of objects.

The P-Scales were found to be very useful not only as a measure of outcome but also to assist in planning the educational support and developing appropriate activities and can also support the implementation of a curriculum. It serves as a common tool shared by educators and health-care professionals. It became clear that this was the assessment tool of choice with which to measure educational progress, particularly as elements thereof will probably be integrated into the new national curriculum for children with intellectual impairments still being developed, by a task team for the National Department of Education.[14]

It is a low-cost high-relevance tool which can be implemented in the interim alongside the South African National Curriculum Framework (NCF) for children 0–4 years (Department of Basic Education 2014). The content of this curriculum addresses the cognition of children 0–4 years and can partly address the learning needs of CSPIDs of all ages. P-Scales as an assessment tool can be implemented from the age of 5

years. Yet the principles of exposure to stimulation, coactive exploration and supported participation can be applied to all, irrespective of age.

To align with the subject areas outlined in the NCF, the terms *Communication* and *Exploring Mathematics* are suggested until the final PID curriculum becomes available. It is imperative that the subject of PSHE and Citizenship become part of the base line data set. It is advised that thought should be given to the eventual inclusion of *Music* as well as *Art and Design* as subject areas, addressing the priority area of sensory awareness and perception (Qualifications and Curriculum Authority 2001). Given the contextual constraints and the fact that the project is still being developed, the authors are of the opinion that the current inclusion of more subject areas is not currently advisable.

The distribution of peaks, which indicates a substantial number of children are performing at a relatively high level, may be useful in identifying children who may be performing at higher levels and are thus inappropriately placed in centres for CSPID. At an individual level, the results of the P-Scales can be utilised to target specific areas of weakness. As case discussions with parents and care staff are part of routine work for CSPID, it will be possible to integrate P-Scales into this process. These guidelines thus give all those involved in the educational stimulation of the child a 'small steps framework' (Mittler 2002) that responds to the diverse educational needs of CSPID. It is a very practical guide to appropriately address learning challenges, which respond to diverse need in learning, facilitate

[14] .Department of Basic Education (2015) The draft South African policy framework for the provision of quality education and support to children and youth with profound intellectual disability.

inclusion and display ways to overcome barriers to learning.

Regular, routine P-Scale assessments will enable charting of the learners' progress. This information is useful to monitor progress over time, assess the effectiveness of intervention and to identify where further support is needed. At a policy level, an analysis of the differential performance on the different scales can inform curriculum development and lead to a greater understanding of the inter-relationship of the different skill categories (Qualifications and Curriculum Authority 2001). In addition, those centres or intervention programmes that are associated with the greatest improvement in the learners' functioning should be identified and should be emulated. The authors recommend that the P-Scale results to be administered by CEMIS, just as the examination results of mainstream school children are retained and coordinated. In this way, each child will become visible to the relevant authorities.

However, the appropriate use of the scales requires training to ensure standardisation of assessment across children, team members and centres. This training should be incorporated into capacity building and professional development of CSPID team members.

The use of the WeeFIM is not recommended for the general routine assessment of CSPID. Although the WeeFIM is a standardised assessment tool, it includes the term of maximal independence. Children with profound disability will always be dependent in many areas of self-care and other activities of daily life. With the exclusion of the WeeFIM due to cost and time implications, the database had a gap in the important area of self-care assessment. The authors identified the need to develop or identify an appropriate self-care classification system for children comparative to the other classification systems. This is a matter of urgency, as developing self-care skills is an essential component in educating CSPID. It is advisable that this tool be developed within the contemporary framework of a support model (Buntinx & Schalock 2010) which takes into account not only the child's abilities but contextual specific elements.

The development of the database was supported by grant funding, and the collection and entry of the data onto a mobile tablet were done by a research assistant, supported by the grant. The analysis and reporting were done in collaboration with academic partners at the University of Cape Town. The process was enriching for both parties and demonstrated the value of academic and public partnerships. However, this model is not sustainable and there is a need to institutionalise the collection, storage, analysis and dissemination of reports and monitoring of the results. This would, in the light of the ruling of the High Court, appear to be a responsibility of the education authorities who have the capacity and structure within CEMIS to perform these functions. Hopefully, this initiative of the CSPID team in identifying and piloting a viable database will inform the future integration of information relating to CSPID into the system that collects and manages equivalent data for all children attending schools. This will go some way in ensuring that the educational and other needs of learners who have severe and profound cognitive impairments are adequately addressed, especially those that have not been enrolled in centres or accommodated in schools. In time, after implementation in the field, the resultant core data set has the potential to form a reference to other countries in Southern Africa, possibly even to more low- to middle-income countries.

Conclusions

It is clear that the development of this database represents the first steps on a long road. In the near future, the use of the database can be rolled out in all the CSPID districts, and repeated assessments of functioning at regular intervals can start. There is no doubt that the database will undergo many amendments as deficiencies and redundancies are identified with use. However, it is likely that a core set

of information will be collected and over time, an overall picture of the needs and capabilities of CSPID will emerge. This information will be useful for service planning and monitoring. At an individual level, regular assessment of the performance levels of the children will give parents, therapists and care workers useful information not only with regard to current performance, strengths and challenges but also in terms of the development and emerging needs of the children. The authors maintain that if a system of data collection is instated by the educational authorities, these most vulnerable of children will become visible and their right to education, as endorsed by the court ruling, will be adequately addressed.

Acknowledgements

Thanks are extended to all members of the WCED CSPID team who participated in this process. Your dedication and commitment to the children in your care is commendable. The collaboration of parents, children and caregivers in the pilot study is also recognised. Funding from the CHEC/WCG Joint Funding is gratefully acknowledged. The contribution of Professor Roy McConkey to the conceptualisation of the database is gratefully acknowledged.

Competing interests

Several of the authors are employed by the WCED and thus have an interest in the introduction of an appropriate database for collecting educational information on children with severe and PID. There are no other financial or personal competing interests.

Authors' contributions

K.S. conceptualised the paper, collected data and analysed the results. L.C. was involved in data collection and management. W.v.R. conceptualized the paper and analysed the results. E.K. collected data and analysed the results. J.M. and H.V. conceptualized the paper. J.J. conceptualized the paper and analysed the results. All of the above contributed to the final draft of the paper.

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Appendix 1

Appendix: Items included in the final database

1. Unique number
2. Surname
3. Name
4. Date of birth
5. Address
6. Centre
7. CSPID team linked to centre
8. Home language
9. Gender
10. Social circumstances home – family structure
11. Social economic status – family income category
12. Grant
13. Transport
14. Assistive devices – wheelchair
15. Buggy
16. Splints
17. Standing frame
18. Hearing aid
19. Glasses
20. AAC
21. Level of educational support
22. ICD11 diagnosis
23. Probable health condition
24. Co-morbid probable health condition
25. Aetiology
26. Chronic medical conditions
27. Outcome – what has happened to the child who left the centre
28. Chronic medication category
29. Chronic medication 1
30. Chronic medication 2
31. Medical intervention
32. Therapeutic intervention (non-CSPID)
33. Other services available at the centre, for example, horse riding
34. Date of assessment of classification systems (GMFCS, MACS and CFCS) (self-care)
35. MACS score
36. GMFCS score
37. CFCS score
38. Self-care classification score – feeding
39. Self-care classification score – drinking
40. Self-care classification score – dressing
41. Self-care classification score – tooth brushing
42. Self-care classification score – toileting
43. Self-care classification score – total
44. Date of assessment P-scales
45. P-Scale score Communication – speaking
46. P-Scale score Communication – listening
47. P-Scale score Exploring Mathematics
48. P-Scale score Physical Education
49. CSPID interventions
50. Date of reassessment of classification systems
51. MACS score
52. GMFCS score
53. CFCS score
54. Self-care classification score – feeding
55. Self-care classification score – drinking
56. Self-care classification score – dressing
57. Self-care classification score – tooth brushing
58. Self-care classification score – toileting
59. Self-care classification score – total
60. Date of reassessment P-Scales
61. P-Scale score Communication – speaking
62. P-Scale score Communication – listening
63. P-Scale score Exploring Mathematics
64. P-Scale score Physical Education

Appendix J: Demographic and medical characteristics of the children in the Chapter 5 sample.

TABLE 34: HOME LANGUAGE OF PARTICIPANTS IN CHAPTER 5

	Count	Percent
Afrikaans	62	74,7
IsiXhosa	18	21,7
SeSotho	2	2,4
English	1	1,2

n=83

As can be seen in Table 34, the home language for 74.7% of the study population was Afrikaans, followed by IsiXhosa for 21.7%. Most of the children (84.3%) received instruction (the language of learning and teaching) in their home language.

TABLE 35: FAMILY STRUCTURE OF PARTICIPANTS IN CHAPTER 5

	Count	Percent
Both parents	24	28,9
Single parent	26	31,3
Extended family	7	8,4
Foster care	19	22,9
Unknown	7	8,4

n=83

The largest number of participants (33.7%) lived with single parents, followed by 28.9% who lived with both parents. Less than half, only 45.8% of the individual files clearly stated what type of grant the child received. Most of the children (24, 63%) whose files indicated that they did receive a grant were in receipt of the care dependency grant. In 91.6% of cases (76) there was no information related to income of parents/guardians available.

The majority (81.9%) did not have a diagnosis specified by a medical practitioner. As can be seen in Table 36, the most common probable health condition was found to be Cerebral Palsy (25.3%), followed by Epilepsy (18.1%) and Childhood Behavioural Disorders (10.8%).

TABLE 36: PROBABLE HEALTH CONDITIONS OF PARTICIPANTS IN CHAPTER 5

	Count	Percent
Cerebral Palsy	21	25.3
Epilepsy	15	18.1
Childhood behavioural disorders	9	10.8
Down's syndrome	8	9.6
Idiopathic intellectual disability	8	9.6
Alcohol use disorders	8	9.6
Other neurological disorders	4	4.8
Other chromosomal anomalies	3	3.6
Other congenital anomalies	2	2.4
Acquired brain damage	2	2.4
Neural tube defects	1	1.2
Sense organ disease of eyes	1	1.2
Spinal cord injury	1	1.2

n=83

As indicated in Table 37, 45.8% of the children in the sample had only one probable health condition associated with the severe or profound intellectual disability. Thirteen children had epilepsy as a second diagnosis, followed by visual impairment in 12 of the children.

TABLE 37: PROBABLE CO-MORBID HEALTH CONDITIONS OF PARTICIPANTS IN CHAPTER 5

	Count	Percent
None	38	45.8
Epilepsy	13	15.7
Vision loss	12	14.5
Other neurological conditions	7	8.4
Childhood behavioural disorders	7	8.4
Alcohol use disorders	2	2.4
Acquired brain damage	2	2.4
Hearing loss	1	1.2
Other mental and behavioural disorders	1	1.2

n=83

Most children (55%) did not have any chronic medical conditions indicated in their files. The most prevalent medical conditional was of a respiratory nature, followed by genitourinary and skin diseases (Table 38).

TABLE 38: ASSOCIATED MEDICAL CONDITIONS OF PARTICIPANTS IN CHAPTER 5

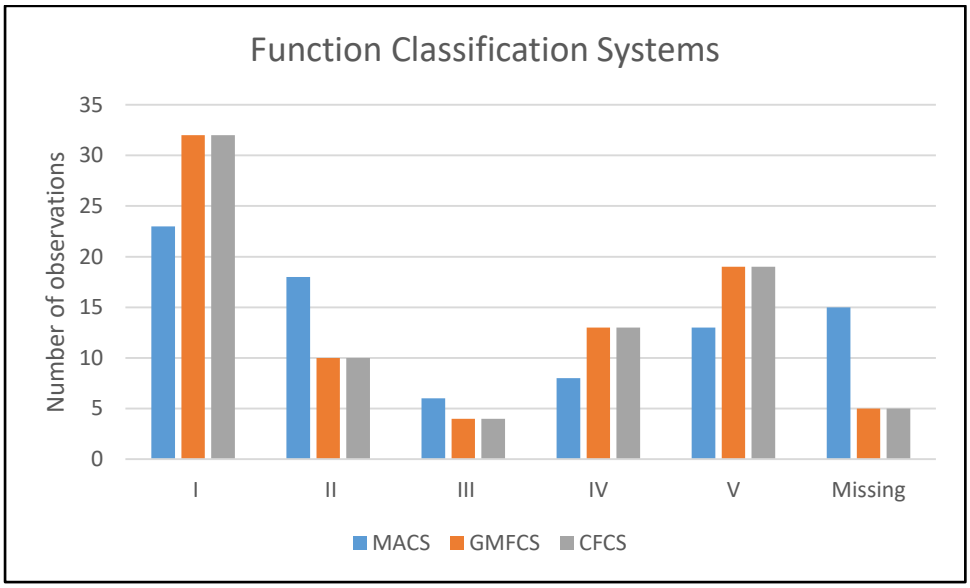
	Count	Percent
None indicated	55	66.3
Respiratory infections	7	8.4
Genitourinary disease	5	6.0
Skin diseases	5	6.0
Oral conditions	4	4.8
Digestive disease	3	3.6
Tuberculosis	2	2.4
Otitis media	1	1.2
Endocrine, blood and immune disorders	1	1.2

n=83

The profile of the children in terms of hand function, gross motor and communication abilities according to the function classification systems (see 3.1.2) is depicted in

n=83

Figure 25.

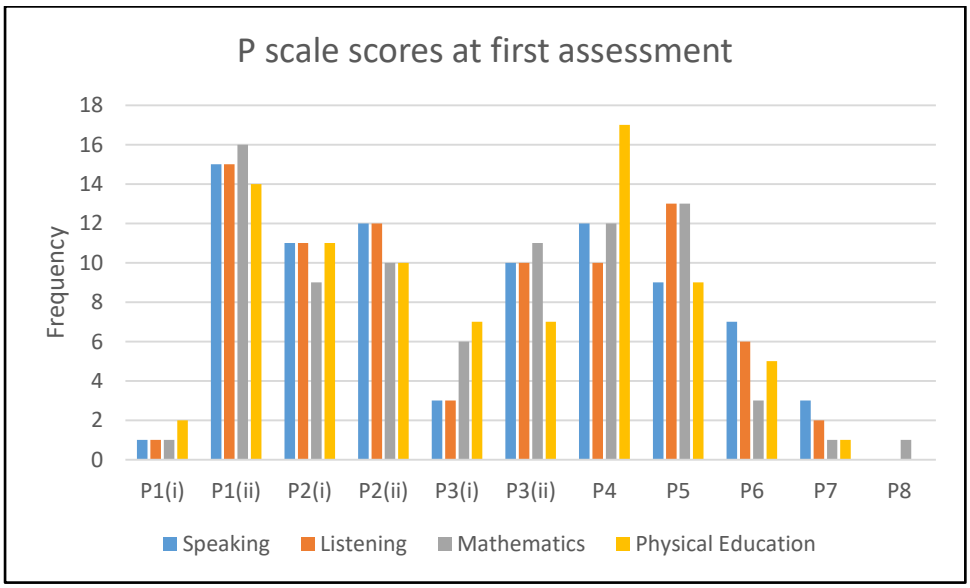


n=83

FIGURE 25: FUNCTIONAL ABILITIES ACCORDING TO FUNCTION CLASSIFICATION SYSTEMS (CHAPTER 5)

The profile in terms of the ability to participate in structured educational activities on initial assessment is depicted in *n=83*

Figure 26.



n=83

FIGURE 26: ABILITIES TO LEARN AND APPLY KNOWLEDGE ACCORDING TO P SCALES (CHAPTER 5)

The amount of support needed for self-care activities as indicated on their Individual Support Plan (ISP) on second assessment is summarised in Table 39. The information was unavailable for 31.3% of the children, 34.9% of the sample needed maximal support in terms of self-care while only 9 children were able to execute self-care tasks with a fair amount of independence.

TABLE 39: SUPPORT NEEDS FOR SELF CARE OF PARTICIPANTS IN CHAPTER 5

	Count	Percent
Maximal support	29	34.9
Moderate support	7	8.4
Minimal support	7	8.4
Supervision	5	6.0
Independent support	9	10.8
Missing	26	31.3

n=83